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**Stigma, Social Comparison and Self-esteem in Transition Age  
Adolescent Individuals With Autistic Spectrum Disorders and  
Individuals With Borderline Intellectual Disability**

Major Research Project and Clinical Research Portfolio

Volume 1

(Volume 2 Bound Separately)

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September 2014



**UNIVERSITY  
of  
GLASGOW**

*Submitted in part fulfilment of the requirements of the Degree in Doctor of Clinical  
Psychology (D.Clin.Psy)*

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## **Acknowledgments**

I would like to thank Professor Andrew Jahoda for his patient guidance throughout my research. I am also very grateful to all of the young people who agreed to take part in the project. It was a privilege to share time with them and to hear about their views and experiences.

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## **Chapter 1**

### **Systematic Literature Review**

#### **Anxiety Treatments for Adolescents with Autistic Spectrum Disorders**

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Prepared in accordance with guidelines for submission to Journal of Intellectual Disability Research (see Appendix 1.1).

## **Abstract**

**Background:** The challenges of the adolescent years may be particularly challenging for those with ASD. Adolescents with ASD have been shown to have a greater risk of experiencing anxiety disorders. As Cognitive Behaviour Therapy (CBT) is the recommended treatment for anxiety disorders, this review systematically examined studies examining CBT treatments for anxiety disorders in adolescent ASD populations.

**Materials and methods:** Electronic Databases were searched for articles published from 1990 onwards. A hand search was conducted of relevant journals and the reference lists of selected articles. Six studies were identified. Four randomised control trials were clustered together. One randomised control trial describing a treatment involving both social skills training and CBT, and one study of a CBT intervention using a case series approach, were examined separately. A structured methodological quality rating tool was used to evaluate all studies.

**Results:** The ages of participants varied between studies with only one study including only teenagers. Studies differed in how they adapted CBT interventions to meet the needs of an ASD population and also in the specific anxiety diagnoses that they sought to treat. Although five studies found a positive effect, the only study to use an active control found that CBT treatment was not significantly more effective than attention control involving social activities.

**Conclusions:** Results suggest that CBT based interventions may be useful with adolescent ASD populations. However further randomised studies using attention controls solely focused on adolescent populations would be helpful.



Adolescence is a period of significant physiological and psychological development during which young people increasingly differentiate themselves from their parents and place greater significance on their peer relationships (Oland and Shaw, 2005). During adolescence the combination of physical changes, such as the development of secondary sexual characteristics and brain development, along with increasing social pressures has been linked to the increased occurrence of mental disorders within adolescent populations (Herpertz-dahlmann and Remschmidt, 2013). A study of the prevalence of mental health disorders within children and adolescents within UK populations found that children aged 13-15 were significantly more likely to be diagnosed with an anxiety disorder than children in younger age ranges (Ford, et al., 2003).

The Scottish Government's guide to delivering evidence based treatments (The Psychological Therapies Matrix, 2011) recommended the use of group and individual Cognitive Behavioural Therapy (CBT) interventions for children with moderate to severe anxiety disorders and this is supported as an effective treatment by a Cochrane systematic review on the use of CBT for children and adolescents with anxiety disorders (James, et al., 2013). Although there is increasing evidence supporting the use of CBT to treat anxiety disorders within neuro-typical populations, relatively little evidence exists regarding the treatment of anxiety disorders within adolescent populations with Autistic Spectrum Disorders (ASDs). ASD is defined by difficulties with social communication and interaction, and restricted, repetitive, patterns of behaviour, interests or activities (American Psychiatric Association, 2013), recognised as a risk factor for experiencing elevated levels of anxiety, with prevalence rates for at least one DSM-IV anxiety disorder reported to be as high as 39.6% (American Psychiatric Association., 2000; Van Steensel, et al., 2011) for children and adolescents with ASD. Whilst individuals with ASD face the same experiences during adolescence as all teenagers, the central difficulties of the condition could pose some additional burdens. In particular the social pressures of adolescence may present a

particular problem as social difficulties are a defining factor of ASD (Sukhodolsky, et al., 2013). Being aware of these social difficulties could increase the anxiety level of adolescents with ASD and make it more difficult for them to function in social situations (Attwood, 2000; White, et al., 2010). In turn this can potentiate anxiety and limit opportunities for these adolescents to develop their social skills if it leads individuals to avoid further interactions (White et al., 2013).

Despite the recognition of higher prevalence rates for anxiety within ASD populations, the core communication difficulties of the condition may mean that it has a different presentation within this population. In particular, even for those with good verbal skills, anxiety may become apparent through increases in restricted and repetitive patterns of interest or through other behaviour changes (White et al., 2010). It has also been suggested that the way in which anxiety is manifested by some individuals with ASD may lead to anxiety going unrecognised or being misinterpreted as a symptom of their ASD rather than a co-morbid anxiety disorder.

Research into anxiety within ASD populations is complicated by its co-morbidity with Intellectual Disabilities (IDs). Around 30% of people with ID will also have an ASD (Emerson and Baines, 2010). Studies focusing on interventions with individuals who have ASD may exclude those with ID and studies focusing on treatment for individuals who have ID may exclude those with ASD. Consequently, those with both ID and ASD receive little study.

Another difficulty in relation to co-morbidity of ASD and ID relates to social anxiety. A meta-analysis of a non-ASD population found that studies reporting a lower mean IQ were associated with higher prevalence rates for social anxiety disorder (Van Steensel et al., 2011). This runs counter to the current hypothesis that individuals with higher functioning ASD may have greater awareness of their difficulties and subsequently be more likely to

experience social anxiety (White et al., 2010). Some studies have combined CBT interventions for anxiety with treatment of the social skills deficits which characterise ASD (e.g. White et al., 2013). While this is appropriate due to the specific social difficulties associated with ASD, the combination of different treatment components complicates the evaluation of treatment effectiveness, as the main underlying mechanisms of change may only be in one of these areas.

Although the use of CBT interventions for anxiety within ASD populations is limited compared to the evidence within neuro-typical adolescent populations (James et al., 2013), two meta-analyses were identified which examined the use of CBT to treat anxiety for children and adolescents with ASD (Sukhodolsky et al., 2013; Van Steensel et al., 2011). Whilst these reviews offered support for the efficacy of CBT interventions for treating anxiety within child and adolescent ASD populations they did not provide explicit evaluation of the methodological quality of the studies included. Due to the specific developmental challenges faced within adolescence, particularly relating to social abilities, the current review focuses on studies examining the use of CBT within adolescent ASD populations and provides explicit evaluation of the methodological quality of studies. The paucity of relevant studies of CBT for adolescent participants meant that studies incorporating social skills elements were included within the current review, provided that they described a CBT focused intervention for anxiety.

## **Research Question**

This systematic review aims to determine whether CBT is an effective treatment for anxiety in adolescent ASD populations.

## **Method**

### **Search Strategy**

In order to identify papers relevant to the current review an electronic search of databases was conducted on the 7<sup>th</sup> of January 2014. The following search terms were developed covering the four main areas of ASD, CBT, Anxiety and age:

1. ASD OR ASC OR Autis\* OR Asperger\*
2. Cognitive beh\* OR CBT
3. Adolesc\* OR Teen\*
4. Anxiety

These search terms were used to search the EBSCOhost system, CINAHL, Psych Articles, Medline and the Psychology and Behavioural sciences collection. The same terms were also used to search Web of Science, ProQuest Dissertations and theses: UK and Ireland, and Scopus. All databases were searched for the time period 1990-2014. Each of the database searches were carried out separately to prevent any potential interactions between different databases that could have interfered with the results.

Results were initially examined for suitability based on the titles of the papers. Following the removal of duplicates, the abstracts of all remaining papers were read for suitability. Finally, full text was acquired for all studies selected as relevant following the reading of abstracts.

In order to identify further papers the reference lists within relevant studies were examined, and a hand search of electronic records of two relevant databases was carried out. Papers with relevant titles were then subject to the same examination for suitability based on abstracts and full texts.

## **Inclusion/exclusion criteria**

All papers identified from database searches were screened against inclusion/exclusion criteria through three stages: titles were examined, abstracts were read and finally the full texts of remaining studies were read.

Studies were included if they:

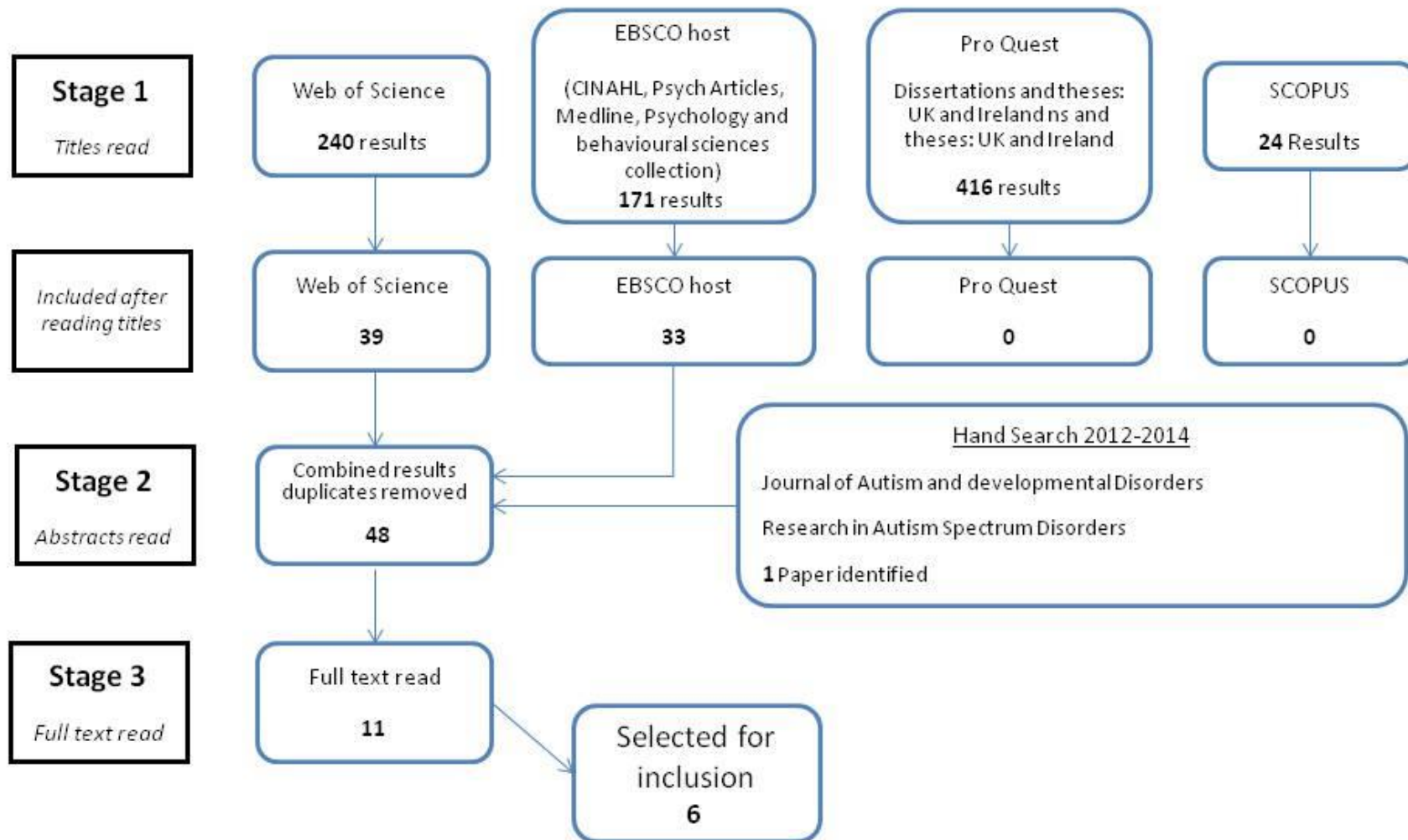
- Used quantitative methods.
- Included participants with ASD within the age range 13-19. It is recognised that adolescence is a period of development that is difficult to demarcate (Sacks, 2003) The World Health Organisation (WHO, 1986) define adolescence as approximately the period between ages 10 and 19. During this period individuals develop a sense of self and increasingly differentiate from their parents as peer relationships become increasingly important (Kramer et al., 2013; Tantam 2000). Within the current study, the age range of 13-18 years was used, as this focused on the age group of individuals who would be attending secondary education until the period of transition beyond school.
- Described treatment of anxiety using a Cognitive Behavioural Therapy based approach.
- Were published in English in peer reviewed journals or were published thesis abstracts describing outcomes.

Studies were excluded if they:

- Were not published in peer reviewed journals
- Were single case studies.
- Focused solely on OCD.

Figure 1 shows the process of study selection.

Figure 1: *Flow chart showing study selection*



## **Methodological appraisal of included studies**

### **Study Design**

Due to the limited number of studies examining CBT interventions with adolescent ASD populations, non-randomised control trial (non-RCT) studies were included within the current review. It was appropriate and The National Institute of Clinical Excellence Guidelines (NICE, 2006) were used to categorise the study designs. The highest level (A) was given to Randomised Control Trials; the second level (B) was for non-randomised control trials and the lowest level of design (C) was assigned to studies using case series designs.

### **Study Quality**

Each study was then assessed using an adapted version of the appraisal checklist developed by Moga, Guo, Schopflocher and Harstall (2012; Appendix 1.2) to assess how it was conducted. This measure consisted of the eleven quality criteria described below which were rated as being present or absent:

**Criterion 1-** Studies were required to clearly describe the aim, hypothesis or study objective within the abstract, introduction or methods section.

**Criteria 2** - Studies were required to specify the tests used and to describe the details of the maximum time period for test administration.

**Criterion 3** – The tests used to assess ASD and IQ at the point of entry into the study needed to be named in order to receive a positive score. It was acceptable for the measures to have been recently administered by other clinicians.

**Criterion 4** - Clear description of the intervention was required comprising number and duration of intervention sessions, attendees and the areas that were covered by the

treatment. For RCT trials this also had to include full details of the randomisation process used.

**Criterion 5** - Suitable measures of fidelity were defined as the use of a checklist or similar measure rated by independent evaluators for a sample of treatment sessions.

**Criterion 6** - Studies scored positively for relevant outcomes being appropriately measured if they described a specific measure of anxiety administered pre and post treatment. The majority of studies did not include an attention control.

**Criterion 7** - Studies received a positive score for the use of independent evaluators if independent evaluators, who were blind to the participants' treatment group, recorded their responses to measures or interviews.

**Criterion 8** - Tests were deemed to be appropriate in evaluating relevant outcomes if the studies described a clear rationale for the approach taken to statistical analysis.

**Criterion 9** - Studies were required to provide an estimate of the random variability in their data analysis (e.g. standard error, standard deviation, confidence interval for all relevant primary and secondary outcomes).

**Criterion 10** - In order to meet this criterion, the conclusions of the study were required to be supported by the results.

**Criterion 11** - Studies were required to have a specific statement regarding sources of support or competing interests to receive a positive score, i.e. they were required to explicitly state that there were no competing interests.



**Reliability of quality rating.** The papers were reviewed twice, by the main author and subsequently by a second independent rater who was another Trainee Clinical Psychologist. A Kappa statistic of 0.90 showed good inter-rater agreement. Disagreements were resolved by discussion between raters. The results of the quality evaluation are shown in Table 1.

Table 1: *Quality criteria results*

|  | <b>Reaven et al.<br/>(2012a)</b> | <b>McNally Keehn,<br/>et al. (2013)</b> | <b>Chalfant et al.<br/>(2006)</b> | <b>Sung et al.<br/>(2011)</b> | <b>Reaven et al.<br/>(2012b)</b> | <b>White et al.<br/>(2013)</b> |
|--|----------------------------------|---|-----------------------------------|-------------------------------|----------------------------------|--------------------------------|
| 1. Hypothesis/ aim clearly explained   | ✓                                | ✓                                       | ✓                                 | ✓                             | ✓                                | ✓                              |
| 2. Standardised measure of anxiety used for inclusion                            | ✓                                | ✓                                       | ✓                                 | ✗                             | ✓                                | ✓                              |
| 3. Standardised measure of IQ used for inclusion                                 | ✓                                | ✓                                       | ✗                                 | ✗                             | ✓                                | ✓                              |
| 4. Intervention clearly described  | ✓                                | ✓                                       | ✓                                 | ✓                             | ✓                                | ✓                              |
| 5. Suitable measures of fidelity used  | ✓                                | ✓                                       | ✗                                 | ✓                             | ✗                                | ✓                              |
| 6. Relevant outcomes appropriately measured before and after intervention        | ✓                                | ✓                                       | ✓                                 | ✓                             | ✓                                | ✓                              |
| 7. Relevant outcomes assessed blinded to intervention status or group            | ✓                                | ✓                                       | ✓                                 | ✓                             | ✗                                | ✓                              |
| 8. Appropriate statistical tests used to assess relevant outcomes                | ✓                                | ✓                                       | ✓                                 | ✓                             | ✓                                | ✓                              |
| 9. Study provides estimates of random variability in data                        | ✓                                | ✓                                       | ✓                                 | ✓                             | ✓                                | ✓                              |
| 10. Are the conclusions of the study supported by the results                    | ✓                                | ✓                                       | ✓                                 | ✓                             | ✓                                | ✓                              |
| 11. Are both competing interests and sources of support for the study described? | ✓                                | ✗                                       | ✗                                 | ✗                             | ✗                                | ✗                              |
| Total criteria met   | 11                               | 10                                      | 8                                 | 8                             | 8                                | 10                             |

## Overall Study Rating

**Scoring the Quality Assessment.** The quality criteria generate a range of possible scores from 0 to 11. However, as some criteria were viewed to be more important than others, a set of “essential” criteria were required to be met for a study to be considered as being of the highest quality. The first “Essential Criterion” was the use of a measure of treatment fidelity (*Criterion 5*), to ensure the study maintained the stated therapeutic regimen. While it could be argued that focusing on treatment fidelity reduces the scope to adapt treatments to meet individual client the aim was to establish how individuals with ASD responded to key CBT concepts and methods. The second “Essential Criterion” was the use of independently rated scores (*Criterion 7*). This was viewed as essential as it eradicates the main source of experimenter bias. Finally, in order for Randomised Control Studies to receive the highest rating, they were required to randomly assign participants to each arm of the study.

To provide an overview of the quality of each study, studies were first categorised according to the type of design used. The highest rating of “A” awarded to Randomised Control Trials, the second level of “B” awarded to Non randomised control trials, and the lowest rating of “C” awarded to case series designs. Following this, studies were categorised as being well conducted (++), moderately well conducted (+), or not well conducted (-). For a study to be considered “*Well conducted*” it had to meet more than seven of the eleven criteria and all three “Essential Criteria”. A “*Moderately well conducted*” study had to meet more than seven of the eleven criteria with no restriction on essential quality criteria. A study was deemed “*Not well conducted*” if it did not meet at least 7 of quality criteria.

## Results

The six studies in this systematic review can be grouped into three categories based on differences in method and treatment. Therefore, the studies have been analysed separately in the following groups:

- Four randomised control trials of CBT for anxiety (Table 2).
- A case series study of CBT for anxiety with an integrated social skills component. (Table 3).
- A randomised control trial of a combined CBT and social skills intervention for anxiety (Table 4).

Quality criteria scores met by each study are shown in Table 1 and their overall ratings in Tables 3 -5. Two studies met the highest quality of Well conducted RCT (A++) (Reaven, et al., 2012a; White et al., 2013). Three studies had the highest level of evidence with a moderate quality rating (A+). One study had met the moderate category for the lowest level of acceptable design (C+). No studies were excluded due to being of low methodological quality (-).

## **RCT studies of CBT for anxiety**

**Overview.** As shown in Table 2, although studies were selected due to their inclusion of adolescent participants, the mean ages of participants was below 13 years across all studies. All of the studies checked that groups were matched in terms of demographic factors although there were some differences in the demographic factors examined. Sung et al. (2011) did not report any measure of socio-economic status, two studies described parental educational attainment (McNally Keehn, et al., 2013; Reaven et al., 2012a) and Chalfant et al. (2007) reported parental income. One study was carried out in Singapore with a majority of Chinese participants. The remaining studies were conducted with primarily Caucasian participants.

Table 2: *RCT studies of CBT for anxiety*

| Author, intervention characteristics, design and quality rating   | Sample Age, gender  | ASD diagnosis <sup>*1</sup> , IQ  | Anxiety diagnosis   | Outcome measures                                       | Main Outcomes  | Methodological Issues  |
|---|---|---|---|--|--|--|
| <p>Reaven et al. (2012a)</p> <p>12x 90 min sessions with children and parents.</p> <p>Token reinforcement for in-group behaviour, use of worksheets and multiple choice lists, written examples of core concepts, hands-on activities, emphasis on creative expression, use of video, parent curriculum.</p> <p>RCT (A++)</p> | <p>50 participants (48 male, 2 female)</p> <p>Age 7-14 (mean for CBT=10.5, mean for TAU=10)</p> <p>29.2% of sessions independently rated using a checklist.</p> | <p>ASD: ADOS<sup>*2</sup> SCQ<sup>*3</sup></p> <p>IQ: WASI<sup>*4</sup></p> | <p>SCARED<sup>*5</sup>: clinically significant scores for SEP, SOC, GAD</p> | <p>ADIS<sup>*6</sup> used to code CSR<sup>*7</sup></p> | <p>CSR: Significantly greater reductions in scores for CBT group according to ADIS. Separation anxiety, (<math>F(1,40)=4.21, p=0.05, d=0.74</math>); Social anxiety, (<math>F(1,40)=6.04, p=.02, d=0.66</math>); specific phobia, (<math>F(1,40)=14.45, p=0.0001, d=0.70</math>); and Generalised anxiety, (<math>F(1,40)=8.11, p=0.007, d=0.87</math>)</p> <p>ADIS-Parent<br/>Significant reductions for overall number of anxiety disorders for treatment group, not present in TAU group (<math>F(1, 42)=5.39, p=0.03, d=0.71</math>).</p> <p>CGIS<sup>*8</sup>-Improvement: Significant improvement for CBT group compared to TAU.</p> <p>SCARED child and parent version- baseline and 3 and 6 month follow-up, for those returning measures treatment gains were maintained.</p> | <p>No active control</p> <p>69% of TAU group received social skills treatment.</p> |

|  |   |  |  |   |   |   |
|--|---|--|--|---|---|---|
| <p><b>McNally Keehn et al. (2012)</b></p> <p>16 x 60-90 min individual sessions. Plus two parent only sessions.</p> <p>Post session review, additional visual &amp; written material, concrete language, focus on participant's interests, sensory stimulation, assistance with writing tasks, focus on individual learning style &amp; greater use of reinforcement.</p> <p>RCT (A++)</p> | <p>22 children (21 male, 1 female)</p> <p>Age 8-14 (Mean=11.6)</p> <p>12% of sessions rated for fidelity by independent evaluators using a checklist.</p> | <p>ASD:ADOS</p> <p>IQ: WASI- IQ of 70+</p>   | <p>ADIS: SEP</p> <p>SoP</p> <p>GAD</p>                   | <p>ADIS</p> <p>SCAS<sup>*9</sup>- Child/Parent</p>  | <p>ADIS-P</p> <p>Significant reduction in numbers meeting criteria for primary anxiety diagnosis for treatment group (<math>F(1,20)=12.53, p&lt;0.01, d=1.35</math>) but not for waitlist group.</p> <p>SCAS</p> <p>Marginally significant group x time effect found for child report scores (<math>F(1,20)=6.31, p=0.02, d=6.31</math>).</p> <p>Significant group x time effect for parent scores (<math>F(1, 20)=29.73, p&lt;0.001, d=1.22</math>).</p>   | <p>No active control</p>                                |
| <p><b>Chalfant et al. (2006)</b></p> <p>9x 120 min sessions and 3 follow-up sessions. Concurrent parent only sessions.</p> <p>Visual aids and structured worksheets, focus on concrete activities e.g. relaxation and exposure tasks, role-play, exposure tasks</p> <p>RCT (A+)</p>  | <p>35 participants (35 male, 12 female)</p> <p>Age 8-13 (mean =10.8)</p>  | <p>ASD: Previous documented diagnosis by paediatrician, psychiatrist or clinical psychologist</p> <p>IQ: Review of documentation from previous assessments carried out by allied health professionals.</p> | <p>ADIS: Significant score for SEP, SoP, PD, GAD, SP</p> | <p>RCMAS<sup>*10</sup></p> <p>CATS<sup>*11</sup></p> <p>SCAS- child and parent report</p> <p>SDQ<sup>*12</sup> parent and teacher version</p> <p>ADIS</p> | <p>Significantly higher number of participants in CBT group no longer met criteria for primary diagnosis (<math>t(1,27)=10.41, p&lt;0.01</math>)</p> <p>RCMAS: Significantly greater reduction between pre and post scores for CBT group (<math>t(1,27)=14.89, p&lt;0.01, r^2=0.99</math>).</p> <p>SCAS-C/P: Significantly less anxiety symptoms in CBT group(<math>t(1,45)=9.048, p&lt;0.01, d=4.36</math>)</p> <p>CATS: Significantly greater reduction in number of internalising thoughts for CBT group (<math>t(1,45)=15.78, p&lt;0.01, d=4.70</math>). No change in externalising difficulties.</p> <p>SDQ: Significant reduction in CBT group scores on the emotion scale (<math>t(1,45)=14.69, p&lt;0.01, d=4.38</math>), and the externalising scale (<math>t(1,27)=5.23, p&lt;0.01, r^2=0.96</math>).</p> | <p>No active control</p> <p>No measure of fidelity.</p> |

|   |   |   |  |                                       |   |   |
|---|---|---|--|---------------------------------------|---|---|
| <p><b>Sung et al. (2011)</b></p> <p>16 x 90 min sessions, no parent involvement.</p> <p>Use of structure, visual strategies, role-plays and social stories.</p> <p>RCT (A ++)</p> | <p>70 children (66male, 4 female)</p> <p>Age 9-16 (Mean for CBT=11.33, Mean for SR=11.09)</p> <p>Sessions rated for fidelity by independent evaluators using a checklist.</p> | <p>ASD: ADOS.</p> <p>IQ: WISC-IV<sup>12</sup> VCI of 80 or above, PRI of 90 or above.</p> | <p>No diagnostic criteria beyond having "anxiety related issues"</p> | <p>CGI-Severity</p> <p>SCAS-Child</p> | <p>SCAS-Child: Significantly lower anxiety scores were found for both SR and CBT groups for overall anxiety (<math>F(3,124)=3.03</math>, <math>p=0.04</math>, <math>\eta^2=0.06</math>) and for generalised anxiety symptoms (<math>F(3,129)=3.28</math>, <math>p=0.03</math>, <math>\eta^2=0.06</math>)</p> <p>CGI-Severity</p> <p>No significant between group differences, no within group analysis.</p> | <p>Unclear whether all participants had clinical levels of anxiety.</p> <p>No waitlist control.</p> |
|---|---|---|--|---------------------------------------|---|---|

\*1.SEP=Separation anxiety, SOC=Social Anxiety, GAD= Generalised anxiety disorder,

SoP=Social Phobia, SP=Specific Phobia, PD=Panic Disorder

2.Autism Diagnostic Observation Schedule

3.Social Communication Questionnaire

4.Wechsler Abbreviated Scales of Intelligence

5.Screen for Childhood Anxiety and Related Emotional Disorders

6.Anxiety Disorders Interview Schedule for DSM-IV

7.Clinician Severity Rating

8. Clinical Global Impressions Severity and improvement ratings

9. Spence Children's Anxiety Scale

10. Revised Children's Manifest anxiety Scale

11. Children's Automatic Thoughts scale

12. Strengths and difficulties Questionnaire



As shown in Table 2, all of the studies had criteria for excluding individuals with ID. however the method of confirming IQ differed, with one study relying on previous documentation (Chalfant et al., 2007) rather than conducting a new test. Sung et al. (2011) required participants to have a Verbal Comprehension score of 80 or above and a Perceptual Reasoning score of 90 on the Wechsler Intelligence Scale for Children (WISC-IV; Wechsler 2004) as they reasoned that this would ensure participants had the ability to understand concepts related to CBT treatment.

With the exception of Sung et al. (2011), all studies used an anxiety rating tool to confirm that participants met the criteria for an anxiety diagnosis. However Sung et al. (2011) targeted participants attending outpatient mental health clinics. The Anxiety Disorders Interview Schedule (ADIS; Silverman and Albano, 1996) used by Chalfant et al. (2007) and McNally Keehn et al. (2013) is a semi-structured psychiatric interview which assesses for childhood anxiety disorders and has acceptable test-retest reliability (Silverman, et al., 2001). The Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999) used by Reaven et al. (2012a) also has sound inter-rater reliability and construct validity (Hale et al., 2011).

The lack of a clear anxiety diagnosis category by Sung et al. (2011) presents a challenge in generalising results between studies. There is the risk of comparing a group of individuals with sub-clinical levels of anxiety to a group with clinical levels of anxiety. Although it may be useful to treat ASD populations with subclinical anxiety as a form of preventative care, particularly as it has been suggested that anxiety may be misinterpreted or not recognised in individuals with ASD (White et al., 2010), this would ideally be studied as a separate research stream. For the purposes of the current review the lack of clarity

over anxiety levels represents a weakness as treatment effectiveness may vary between populations with clinical and sub-clinical levels of anxiety.

**Intervention.** All of the studies used existing CBT interventions as a basis for their CBT treatments. However, there were differences in how closely interventions were based on previous programmes. Chalfant et al. (2007) adapted the “Cool Kids” programme whereas McNally Keehn et al. (2013) used an adaptation of the “Coping Cat” programme which was also cited as a source by the remaining two studies (Reaven et al., 2012a; Sung et al., 2011). Across the studies, there was a lack of detail about the specific aspects taken from each intervention programme, which makes it difficult to assess the value of individual treatment components. As shown in Table 2, session number and format varied between the studies. However, all of the studies described group interventions using core concepts of CBT for anxiety, including recognition of somatic symptoms of anxiety, psycho-education about anxiety, use of anxiety management techniques and use of exposure tasks. All of the studies described making adaptations to facilitate engagement of individuals with ASD in the treatment. Common adaptations across studies included greater use of written materials, emphasis on using concrete language and increasing session duration. Two studies also described using role play to teach concepts to participants. Role plays were demonstrated by the facilitators (Chalfant et al., 2007) or by participants themselves using video-modelling (Reaven et al., 2012a).

Studies also differed in the extent to which they involved parents in intervention programmes. Three of the four studies included some form of parent involvement in treatment. Reaven et al. (2012a) included parents in all group sessions alongside their children, whereas Chalfant et al. (2007) conducted separate parent sessions alongside group sessions with young people; McNally Keehn et al. (2013) carried out two parent only sessions alongside a group intervention.

**Clinical outcomes.** As shown in Table 2, all of the studies offered some support for the use of CBT interventions with ASD populations. Reaven et al. (2012a) found that significant reductions in Clinician Severity Ratings (CSRs) from pre to post treatment were reported for the treatment group across each of the four main anxiety disorders measured by the ADIS (Silverman and Albano, 1996). Analysis of Covariance showed reductions in severity for the treatment group: Separation anxiety, Social anxiety, specific phobia, and Generalised anxiety. Participants in the treatment group also showed a significant reduction in the overall number of anxiety disorder diagnoses met. No reduction was found for control condition. Although the Clinical Global Impressions Scale (CGIS-I; National Institute of Mental Health, 1970) can be used to evaluate improvement between two time points, only severity scores were used within the study.

Chalfant et al. (2006) used a number of outcome measures to evaluate the impact of CBT treatment on anxiety (Table 2). At post treatment, a significant group by time interaction was found for the number of DSM-IV diagnoses met, with the CBT group showing a significant reduction in the number of anxiety diagnoses met at post treatment,  $t(1,27)=10.41, p<0.01$ ), and the control group showing no significant reduction. Self-report measures showed that only the CBT group reported significantly less internalising thoughts as measured by the Children's Automatic Thoughts Scale (CATS; Schniering and Rapee, 2002) compared to wait list controls, at post treatment. Similarly the CBT group showed a significant reduction in self-reported anxiety as measured by the Revised Children's Manifest Anxiety Scale (RCMAS). The CBT group reported significantly less symptoms on the Spence Children's Anxiety Scale (SCAS), compared to waitlist controls at post treatment. Parent report SCAS-P scores also showed significant reductions for the CBT group. The same results were found for scores on the Strengths and Difficulties Questionnaire (SDQ) Emotion scale. On the SDQ externalising scale the CBT group also showed a significant reduction in scores. No reduction in externalising scores was found for the control group.

McNally Keehn et al. (2013) found significant group by time interaction for the ADIS-P Interference rating, with the treatment group having lower scores at post treatment. A significant group by time interaction was found for parent report SCAS scores, but not child scores. A significant group by time effect was also found for changes in comorbid diagnoses on the parent version of the Anxiety Disorders Interview Schedule.

Sung et al. (2011) compared group CBT to an active treatment involving a manualised "Social Recreational" (SR) intervention which focused on self-development skills such as learning to cook, taking part in craft activities, and activities to improve motor coordination, plus engaging in group activities designed to develop and use pro-social skills. Although significant reductions were found from child report scores on the Spence Children's Anxiety Scale for overall anxiety and generalised anxiety symptoms across conditions, there were no significant between group differences. Therefore the CBT intervention did not lead to greater improvements than the SR control group.

**Methodological appraisal.** Three studies (Table 2) met the criteria for well conducted designs (McNally Keehn et al., 2013; Reaven, Blakeley-Smith, Culhane-Shelburne, et al., 2012; Sung et al., 2011) as they described the randomisation process used and met the key quality criteria (Table 2). The study by Chalfant et al. (2007) did not include any measure of treatment fidelity and therefore received an acceptable rating. However Chalfant et al. (2007) recognised that the lack of treatment fidelity measures was a methodological weakness. Despite the fact that studies were considered well designed according to the quality criteria used, there were still other weaknesses. For example, there is the possibility of bias in Clinical Global Impression ratings (Reaven et al., 2012a; Sung et al., 2011) as clinicians were aware of whether scores came from the baseline or post treatment period when they produced ratings. Additionally, it is possible that participants may not have provided accurate estimations of their own anxiety symptoms.

**Conclusions.** Four RCTs were reviewed, three meeting good quality criteria and one acceptable. The reviewed studies presented offer some support for the effectiveness of CBT within adolescent ASD populations. There were a number of areas of weakness within the studies. The most significant weakness was the lack of attention controls. Three studies (Chalfant et al., 2007; McNally Keehn et al., 2013; Reaven et al., 2012a) did not include attention controls. This means that it is not possible to assess whether improvements in anxiety symptoms were due to the specific CBT intervention, expectation of improvement or due to treatment components that were not specific to CBT interventions such as having an opportunity to speak about difficulties or the social support from attending a group setting.

Sung et al. (2011) used an attention control but did not find greater improvements for the CBT group over the attention control condition. It is possible that the control condition may have acted as a behavioural exposure to anxiety by encouraging them to take part in core activities, thereby offering participant opportunities to challenge their anxious

thoughts and to overcome their anxiety symptoms. It may be that a group of participants with clinical levels of anxiety would have responded differently to the treatments described.

No study was solely based on CBT with adolescent populations, i.e. all of the study populations included children with none reporting a mean participant age within the teenage range. Although some studies discussed tailoring of treatment to individuals of different ages (e.g. Sung et al., 2011) they did not describe separate manualised treatments for teenagers and children. This makes it difficult to evaluate the impact of specific adaptations made for teenage CBT with adolescent ASD populations. Although this was not the aim of the studies, further research on CBT treatments within adolescent populations would be useful as there are suggestions that this age group may be at particular risk of developing anxiety.

### **Case series: CBT treatment with social skills module**

**Overview.** The Reaven et al. (2012b) study is presented separately as it used a case series design of CBT for anxiety and also described the use of a social skills module as a separate component. The study was the only one included within the present review that described treatment of adolescents with ASD. As shown in Table 3, participant ages ranged from 13-18 years with a mean age of 15.5 years. In common with other studies, the majority of participants were male and Caucasian. All participants were confirmed as having intellectual functioning within the normal range via administration of the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999). All participants had clinically significant levels of anxiety measured by the Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al., 1999).

Table 3: *Case series study of CBT for anxiety with social skills component*

| Author, intervention characteristics, design and quality rating  | Sample Age, gender  | ASD diagnosis, IQ  | Anxiety diagnosis <sup>*1</sup>   | Outcome measures   | Main Outcomes   | Methodological Issues   |
|--|---|--|---|--|---|-------------------------|
| <p><b>Reaven et al. (2012b)</b></p> <p>14x 90 min sessions with one additional booster session. Joint sessions with parents.</p> <p>From FYF (Reaven, Blakeley-Smith, Culhane-Shelburne, et al., 2012) Token reinforcement for in-group behaviour, use of worksheets and multiple choice lists, written examples of core concepts, hands-on activities, emphasis on creative expression, use of video, parent curriculum.</p> <p>Additional modifications for adolescents: social skills module, parent-teen dyadic work to identify primary anxiety diagnoses, use of technology (PDAs), increase in in session exposure tasks, focus on unique challenges of adolescents in parent sessions</p> <p>Case series (C +)</p> | <p>15 Male, 9 female</p> <p>Age 13-18 (mean= 15.5)</p> <p>No measures of treatment fidelity</p> | <p>ASD: ADOS</p> <p>Social Communication Questionnaire (SCQ)</p> <p>IQ: WASI estimated IQ over 70. Or equivalent measure of IQ administered in preceding two years</p> | <p>Clinically significant scores for SEP, SOC, GAD on the SCARED<sup>*5</sup></p> | <p>SCARED Parent and child report.</p> <p>ADIS-P, ADIS-C used to produce CGI-Severity, CGI-Improvement</p> | <p>CGI-Severity: significant reduction in severity scores from pre to post treatment (<math>Z=2.53</math>, <math>p=0.01</math>)</p> <p>CGIS-Improvement, 46% positive treatment response, 33% some improvement, 21% no change.</p> <p>SCARED significant reductions in total anxiety symptoms from pre to post treatment for children (<math>t=3.89</math>, <math>p=0.001</math>) and parents (<math>t=2.87</math>, <math>p=0.009</math>) and from post treatment to follow up for children (<math>t=3.03</math>, <math>p=0.008</math>) and parents (<math>t=3.82</math>, <math>p=0.001</math>)</p> | <p>No control group</p> |

**Intervention.** The study, described in Table 3, used an adaptation of the Facing Your Fears Intervention (FYF) which used other CBT treatment programmes such as the “Coping Cat” as sources for its development. As with other studies, treatment involved the use of core CBT concepts such as graded exposure, management of somatic symptoms of anxiety, use of cognitive control and emotion regulation strategies. Adaptations were also made to the needs of ASD participants, including greater use of visual structure and written materials, and greater opportunities for revision and practice of skills.

The study also incorporated a social skills module focusing on social anxiety symptoms. The social skills intervention involved participants carrying out role plays of anxiety provoking social situations. Role plays were video-recorded and subsequently critiqued by group participants. Although the study described this component as an addition to the CBT treatment it is conceivable that similar content could be covered within other treatments where exposure tasks are developed to address the individual difficulties of participants. An additional modification involved providing participants with hand held Personal Digital Assistant (PDA) devices, to prompt them to use anxiety management techniques and to rate their anxiety and record exposure activities on a daily basis.



**Clinical outcomes.** Significant reductions were recorded for anxiety scores on the Screen for Child Anxiety Related Emotional Disorders (SCARED) for parent scores from pre-treatment to post-treatment and from pre-treatment to follow-up. Similarly significant reductions in anxiety scores were recorded for participants from pre-treatment to post treatment and from pre-treatment to follow-up. Significant reductions were found for severity of anxious symptomatology at post treatment measured by the Clinical Global Impression Scale-Improvement scale.

**Methodological appraisal.** Although this study has the lowest rated method included in the current review (Tables 1 & 2), a case series method could offer the potential benefit of assessing the impact of different treatment components over time, particularly assessing the separate impact of the social skills and CBT components. However, this analysis is not available as components were combined and anxiety measured at pre-treatment, post-treatment and three month follow-up.

The design used meant that it is not possible to assess whether improvements were significantly greater than would have been made over the same time period without treatment. The study also used Clinical Global Impression Scale- Improvement (CGI-I) scores. As has been stated, these scores are reliant on clinician judgement with the possibility of bias. Furthermore, having one of the co-facilitators of the group also completing measures increases the possibility of bias. The lack of a measure of treatment fidelity meant that this study received an acceptable rating.

**Conclusions.** This study is discussed separately due to both the method used and the inclusion of a social skills module within treatment. As the content of the social skills module is not significantly different to exposure tasks that may be included within a CBT treatment it does not necessarily represent an additional active treatment component. Overall the study offers support for CBT interventions for adolescents with ASD, however the weakness of the design means that the evidence has to be treated with considerable caution. Further research with control groups receiving CBT without PDAs and a design controlling for the social skills component would help to clarify the effectiveness of the approach. It would be useful to establish whether the social skills module increases the effectiveness of the CBT treatment. Furthermore, if the social skills module was found to increase the effectiveness of the treatment it would also be useful to establish whether this was due to increasing engagement in treatment by offering strategies to compensate for difficulties related to ASD. Finally, although the study reported that participants engaged with the PDA devices provided, as all participants received these devices, it is not clear whether their use improved engagement over traditional methods.

## **RCT: Combined CBT and social skills treatment**

**Overview.** White et al. (2013) conducted a pilot study using an RCT design. This study is presented separately as it used a combined social skills and CBT intervention for anxiety (Multimodal Anxiety and Social Skills Intervention; MASSI) rather than an adaptation of existing CBT interventions. Participant characteristics are described in Table 4. The majority of participants were male and Caucasian. The study appropriately measured intellectual functioning, and ASD (Table 4). The measures used to examine clinical improvement and diagnostic status were scored by independent evaluators who met with participants prior to, and following, treatment but were blinded to the treatment group.

**Intervention.** White et al. (2013) adopted a different approach to other studies within the present review as it had an integrated focus on social skills and CBT for anxiety, rather than a social skills component added to a CBT treatment. The treatment approach also differed from other studies which focused on group interventions, as it consisted of individual sessions along with a small number of group sessions (Table 4). Although other studies described taking steps to individualise treatment for participants, this was the only study to use individual appointments to develop an individual case conceptualisation. This information was then used to inform the selection of relevant modules from the treatment manual for use in individual sessions. The seven subsequent group sessions were standardised for all participants.

Table 4 : RCT of combined social skills intervention and CBT for anxiety

| Author, intervention characteristics, design and quality rating   | Sample Age, gender  | ASD diagnosis , IQ  | Anxiety diagnosis *1                                  | Outcome measures   | Main Outcomes   | Methodological Issues    |
|---|---|---|---|--|---|--------------------------|
| <p><b>White et al. (2013)</b></p> <p>13 individual therapy sessions lasting 60-70 minutes with parents joining for 15 minutes of education/coaching at the end of sessions. 7 x 75 min group skills practice sessions with an “unaffected peer tutor” were also conducted.</p> <p>40 % (14 of 35) of group and 14 % (25 of 180) of individual therapy sessions were reviewed and independently coded for fidelity by trained coders.</p> <p>Incorporating principles of Applied Behaviour Analysis (ABA), focus of parental and family involvement, role play and exposure, modelling of skills, psycho-education about ASD and anxiety, use of written and creative activities.</p> <p>RCT (A++)</p> | <p>30 (23 male, 7 female)</p> <p>Age 12-17 (mean for MASSI=14 years, mean for WL, 15 years)</p> | <p>ASD: ADOS (Lord et al. 2000)</p> <p>ADI-R (Lord et al. 1994)</p> <p>IQ: WASI</p> | <p>ADIS: significant scores for SoP, GAD, SEP, SP</p> | <p>CASI-Anx<sup>*13</sup></p> <p>CGI-I</p> <p>DD-CGAS<sup>*14</sup></p> <p>SRS<sup>*15</sup></p> <p>PARS<sup>*16</sup></p> | <p>SRS: Significant improvement for MASSI group</p> <p>CASI-Anx: No significant change</p> <p>PARS: No significant change within/between group</p> <p>SRS: Significant improvement for MASSI group (<math>\chi^2=12.86</math>, <math>p&lt;.001</math>, <math>d=1.18</math>).</p> <p>DD-CGAS: Significant group difference with MASSI group showing significant pre-post improvement</p> | <p>No active control</p> |

<sup>\*13</sup> Child and Adolescent Symptom Inventory-Anxiety scale

<sup>\*14</sup> Developmental Disabled Children's Global Assessment

<sup>\*15</sup> Social Responsiveness Scale

<sup>\*16</sup> Paediatric Anxiety Rating Scale

**Clinical outcomes.** The treatment group showed a significant improvement on a measure of global functioning for children with developmental disabilities (DD-CGAS). However there were no significant differences between the groups on the Clinical Global Impressions Scale-Improvement ratings. On the measures of anxiety, the Child and Adolescent Symptom Inventory-Anxiety scale; (CASI-anx) and the Paediatric Anxiety Rating Scale (PARS), no significant differences were found between treatment conditions. In addition to anxiety measures, the study used the Social Responsiveness Scale (SRS; Constantino and Gruber 2005) to examine change in relation to social skills. A group difference was found for improvements on the SRS for the treatment group, suggesting that the intervention did impact on the social functioning of participants.

**Methodological Appraisal.** Although the study received a high rating for design (Table 4) due to its use of blinded evaluators, description of randomisation, and fidelity measures combined with the scores on the rating scale, the focus was on feasibility rather than efficacy of treatment. The authors described their primary intentions as being to test the acceptability of the intervention for participants rather than testing its clinical effectiveness.

**Conclusions.** Although the study was well conducted and the intervention appeared to improve social skills, there was no evidence that the intervention improved anxiety symptoms within adolescent participants.

## **Discussion**

The purpose of the current review was to establish whether CBT interventions for anxiety were effective in adolescent ASD populations. Overall the evidence within the current review suggests that CBT may be an effective treatment for anxiety for adolescents

with ASD. However the evidence-base is extremely limited and therefore conclusions are tentative. The evidence within the current review is drawn from a relatively small number of suitable studies and studies varied in the age of participants included, the anxiety disorders they targeted within treatments, and the interventions used. Two important areas of variation were in the adaptations made to pre-existing interventions, and the inclusion of social skills components.

## **CBT adaptations**

In all of the studies reviewed, interventions were adapted for individuals with ASD. They described enhanced use of visual aids and exposure tasks to provide concrete examples of concepts in different settings. Two studies used video-recordings of modelled activities or role-plays involving participants (Reaven et al., 2012a; Reaven et al., 2012b). While the rationale for the adaptations for the different studies was clear it was not possible to assess the impact of the different adaptations due to the range of methods involved and the variation in application throughout treatment and the lack of process measures, as only pre and post treatment measures were reported.

## **Social Skills**

Social difficulties are a defining factor in the diagnosis of ASD and it is logical that some studies, such as that of Reaven et al. (2012b), involved developing exposure tasks relating to social situations. In general, they included social skills components that are relatively in keeping with standard CBT methods and would not differ significantly from exposure activities that would be suitable for non-ASD individuals with social anxiety. However, the benefits of additional focus on social skills for individuals with ASD remain unclear. White et al. (2013) described a treatment with an explicit focus on improving social skills rather than promoting social skills adaptations in order to facilitate engagement in a CBT anxiety reduction intervention. However, while they found evidence for an

improvement in the participants' social skills, the intervention did not appear to have a significant impact on the participants' levels of anxiety. This might suggest that, despite the social skills deficits underlying the difficulties of those with ASD, a focus on CBT methods may be more effective in reducing anxiety. However the White et al. (2013) study was primarily designed to test the acceptability of the intervention. It would be useful for future studies to examine the effects of social skills components and CBT components. In essence the incorporation of social skills elements within studies may not represent a significantly different experience than incidentally acquiring such skills from engaging in group CBT with social exposure tasks but it is important to know if and in what area any specific therapeutic advantage can be gained.

## **Limitations and Future directions**

The inclusion criteria for all of the studies with a diagnostic anxiety assessment incorporated Generalised Anxiety Disorder, Separation Anxiety Disorder and Social Anxiety Disorder. However, two studies included individuals with Specific Phobia (Chalfant et al., 2007; White et al., 2013), and one study included those with a diagnosis of Panic Disorder (Chalfant et al., 2007). This complicates comparisons by increasing the variability between studies but may also have reduced the strength of the evidence produced if Specific Phobia and Panic Disorder were not as responsive to more general anxiety treatment used in the studies.

The incorporation of Applied Behaviour Analysis described by White et al. (2013) adds another dimension that should be evaluated. Whilst White et al. (2013) presented their study as using a broadly CBT perspective, the incorporation of ABA represents a change in method and theoretical approach.

## **Overall conclusions**

The limited number of available studies focusing on treatment of anxiety within adolescent ASD populations meant that it was necessary to include studies concerning both children and adolescents. As there are significant developmental changes throughout late childhood and teenage years this is a limitation within the current evidence base. The available evidence suggests that there is some support for the use of CBT in adolescent ASD populations. However, future research could benefit from a number of improvements. Focusing on interventions with more limited age groups would allow treatments to consider the specific developmental level of participants and incorporating different treatment approaches may help match individuals to the type of approach that would help them change most readily. Finally study designs which allow different treatment components to be examined would allow the impact of different components to be examined.



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## **Chapter 2**

### **Major Research Project**

#### **Stigma, Social Comparison and Self-esteem in Transition Age Adolescent Individuals With Autistic Spectrum Disorders and Individuals With Borderline Intellectual Disability**

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Disability Research (see Appendix 1.1).

## **Abstract**

**Background:** Young people who have intellectual disabilities (ID) or Autistic Spectrum Disorders (ASD) may experience stigma which can lead to them developing negative views about themselves. However, it has been shown that individuals with ID can mediate the impact of stigma through the comparisons they make with other people. People with ASD might have difficulty making these “social comparisons” because of their social cognitive difficulties. The current study explores whether a group of young people with ASD who do not have an ID or borderline/mild ID, recognise and report experiences of stigma similarly, whether they have similar levels of self-esteem, and whether individuals with ASD make social comparisons in a similar way to individuals with borderline/mild ID.

**Method:** A group of young people with ASD, without learning disability, and a group with borderline/mild ID were recruited. Measures of stigma, self-esteem and social comparison were completed with participants. The social comparison measure was completed in relation to a person described as having a developmental disability and a typically developing individual. A subsample of participants in each group were asked to provide more detailed examples of the types of stigma they experienced to confirm that their reported experiences accurately reflected experiencing stigma.

**Results:** Participants in the ASD group reported more experiences of being made fun of, whereas those in the borderline/mild ID group reported more experiences of being treated differently to their peers. The specific examples of stigma experiences were similar between the groups. Despite experiencing stigma, the self-esteem scores of both groups were positive. The social comparisons that both groups made in relation to developmentally disabled and typically developing peers were also positive. However the ASD group compared themselves significantly less positively to a typically developing peer than to a developmentally disabled peer.

**Conclusions:** Young people with ASD were aware of facing stigma and compared themselves positively to individuals with intellectual and social difficulties, and less positively to typically developing individuals. The study demonstrates that individuals with ASD are able to understand situations and to make comparisons that appear to require a degree of social understanding. It remains uncertain whether making positive social comparisons helped participants to manage the impact of stigma, therefore this is an area that requires further investigation.

## **Lay summary**

**Background:** Like other marginalised groups in society, young people with autistic spectrum disorders (ASD) or intellectual disabilities (ID) can face discrimination from other people who are intolerant and make judgements about their different abilities. The way that young people with ASD or ID compare themselves to different peers might help them to remain positive about themselves despite having difficult experiences of being treated badly (stigma). This study examines the way in which a group of young people with mild/borderline ID and a group with ASD recognise and describe experiences of stigma. The study also examines whether experiences of stigma impact on how people feel about themselves and whether they compare themselves differently to a peer who has an ID and a typically developing peer.

**Method:** A group of young people with ASD and a group with borderline/mild ID were recruited. Participants were asked to complete questionnaires about stigma, self-esteem, and how they compared themselves to other people. The comparison measure was completed twice: participants were asked to compare themselves to a person described as having developmental disability and to a typically developing peer. Smaller samples of participants from each group were asked to describe examples of their experiences of stigma to ensure that they understood what was being asked.

**Results:** Participants with ASD reported more experiences of being made fun of, whilst those with mild borderline ID reported more experiences of being treated differently. The examples of stigma described by each group were similar. Both groups reported feeling positive about themselves despite their experiences of stigma. Both groups also compared themselves positively to a peer with a developmental disability and a typically developing peer, but the ASD group compared themselves significantly less positively to the typically developing peer than the developmentally disabled peer.



**Conclusions:** Young people with ASD recognised that they were treated badly at times and they compared themselves less positively to typically developing peers than to developmentally disabled peers. It was found that these social comparisons differed depending on whether the comparison group was developmentally disabled or typically developing. The study provides limited evidence that young people with ASD may think about their experiences with, and their comparisons to, other people in a similar way to people who do not have ASD.

The current study examines aspects of how young people with borderline/mild Intellectual Disability (ID) and young people with Autistic Spectrum Disorder (ASD), who do not have a learning disability, experience and understand stigma. Individuals with these conditions are likely to display a diverse range of difficulties that are evident in either their behaviour or cognitive functioning. Additionally they are likely to receive different treatment from others, for example they may receive various supports within educational settings, including spending time in separate learning bases. Although difference may be viewed positively in certain circumstances, recognising that one is perceived to be different from others in a negative fashion, is necessary for stigma to be experienced. The period of late adolescence may be particularly challenging for young people with ID or ASD. For example, at a developmental stage where most individuals are becoming increasingly independent, individuals with ID may become increasingly aware of the limitations placed on their own independence (Larkin, et al., 2012). For individuals with ASD, the increasingly complex social demands of late adolescence, when peer relationships become more important, may highlight their social difficulties (Tantam, 2000). Therefore, individuals with ASD and those with ID may be particularly vulnerable to being treated in a stigmatised manner at this stage of their development.

Goffman (1963) defined stigma as an “attribute that is deeply discrediting” and reduces the bearer “from a whole and usual person to a tainted discounted one”. More recently, Link and Phelan (2001) offered a new definition of stigma as a process whereby individuals are labelled as different and these differences are linked to negative stereotypes; labelled persons are placed in distinct categories separating them from non-labelled persons, leading to a loss of status and discrimination. Further, in order for these conditions to lead to stigma a power differential must exist (Link & Phelan, 2001). Stigmatised groups may experience difficulties in various life areas including social relationships, health, employment and educational outcomes (Hatzenbuehler et al., 2013).

Young people with ASD or ID are both subject to diagnostic labels and placed apart from other individuals. The intention behind labelling may be positive and labels may assist an individual accessing support or being understood (Farrugia, 2009). However, the fact that both groups have also been shown to experience increased bullying (Kaukiainen et al., 2002; Little, 2002) may be a consequence of stigmatised attitudes regarding their conditions.

Stigma experiences may have a deleterious impact on wellbeing by undermining a person's sense of self. It has been shown that societal stigma can become internalised and individuals may begin to accept negative labels and judgements, thereby damaging their sense of self-worth (Vogel et al., 2013). Although the relationship between public- and self-stigma has not been explicitly explored in relation to individuals with ID, studies have found that increased awareness of stigma is related to lower self-esteem for people with ID (Paterson et al., 2012; Szivos-Bach 1993).

There is limited evidence demonstrating that stigma is experienced by children and adolescents with ASD (Staniland and Byrne, 2013), and that adolescents with ASD may develop negative views of their difficulties as a consequence of ill treatment from peers (Humphrey and Lewis, 2008). Only one study has investigated the link between stigma and self-esteem within an ASD population, finding that more severe ASD symptomatology was correlated with lower levels of reported stigma (Shtayermman, 2009). This finding may be explained by the core diagnostic features of ASD, namely difficulties in social interaction, communication and repetitive patterns of interest (American Psychiatric Association, 2013). It is reasonable to suppose that individuals with more severe ASD symptoms are likely to have more problems in social interaction, communication and perhaps also intellectual functioning. Thus, they may have greater difficulty in expressing their feelings or have less awareness of being treated in a stigmatised manner. It has also been suggested that individuals with ASD may be subject to greater levels of stigma when their difficulties are

not easily recognised as being a part of a developmental disorder (Ling, et al., 2010). This might mean that because someone with ASD has no obvious signs of difference, their social and communication difficulties could be misinterpreted, resulting in a lack of understanding and subsequent social rejection.

It is possible that individuals with ASD will process and internalise experiences of stigma differently to other individuals due to the fact that perceiving another person's actions as stigmatising is a social judgement. The subjective observations that a person makes in relation to how they are viewed and treated by others significantly contributes to their self-concept (Cooley, 1902; Mead, 1934). Whilst "self-concept" refers to the views that a person holds about themselves, it closely relates to the feelings that an individual holds about their self-worth, i.e. their self-esteem (Swann et al., 2007). It has also been suggested that the way in which an individual views themselves is affected by how they compare themselves to other individuals (Festinger, 1954).

Social comparison theory (Festinger, 1954) proposes that the way in which an individual compares themselves to others affects the evaluations that they make about themselves. For example, when a person compares themselves to someone who performs better than them in a particular area they may judge their own ability negatively and in turn this may have subsequent consequences for their self-esteem. On the other hand, making a comparison with someone who performs at the same or a lower level in a particular area may lead to more positive self-judgements. Studies have found that adolescents with ID are capable of making different social comparisons to different targets and it is suggested that they may use social comparison to counteract the effects of stigma and maintain a positive sense of self (Cooney et al., 2006; Crabtree and Rutland, 2001; Szivos, 1991).

The way in which individuals with ASD and those with ID experience stigma and internalise messages about themselves is of importance, not only because of the broader

evidence about the impact of stigma, but also due to the greater prevalence of mental health disorders within these populations (Hedley and Young, 2006; Mishna, 2003). A meta-analysis of longitudinal studies with non-ID/ASD people found that negative self-esteem predicted both anxiety and depression (Sowislo and Orth, 2013). The same relationship between self-esteem and depression has also been found for individuals with ID and those with ASD (Dagnan and Sandhu, 1999; Hedley and Young, 2006). As has been described previously, the social cognitive difficulties experienced by individuals with ASD mean that they may not internalise stigmatised treatment in the same way as other individuals (Cooney et al., 2006).

It is therefore unclear, from the evidence-base, whether individuals with ASD experience stigma in a similar way to their peers with mild to moderate ID and whether such experiences have the same impact on their sense of self. It is also unclear whether young people with ASD are able to use social comparison to maintain a positive sense of self and counteract their devalued social status. One possibility is that the social cognitive difficulties experienced by individuals with ASD makes them less aware of stigma than those with ID. If young people with ASD are less aware of experiencing stigma it may be predicted that they will also have higher self-esteem than those with ID.

Although there may be relative differences between the abilities of young people with ASD or ID to make social comparisons, it may be expected that both groups will tend to view themselves more favourably in relation to a peer who is described as having social and cognitive impairment than to a typically developing peer. Finally, for both groups, it may be expected that having higher self-esteem will be positively associated with more positive social comparison.

## **Hypotheses**

The following hypotheses were examined:

### *Between group hypotheses*

1. Individuals with ASD will be less aware of stigma than those with ID.
2. Individuals with ASD will have higher self-esteem than those with ID.

### *Within group hypotheses*

3. Reported stigma scores will be negatively associated with self-esteem scores for both groups.
4. Both groups will make significantly more positive social comparisons when comparing to a target individual with developmental delay than when comparing to a typically developing individual.
5. For both groups, self-esteem will be positively associated with more positive social comparisons when comparing to others.

## **Method**

### **Participants**

Twenty-three participants identified as having borderline/mild intellectual disabilities (ID) and sixteen participants identified as having Autistic Spectrum Disorders (ASD) without learning disability, were recruited. All of the participants in the ID group were recruited from schools and colleges within the Highland region of Scotland. Six participants from the ASD group were recruited from an organisation offering outreach support to young people with ASD in the West of Scotland. All participants were in, or had been educated in, mainstream settings, although six participants were currently attending a college course catering for individuals with disability. Participants who were included in the study were included if they met the following criteria: i) were aged 16-21 years, ii) were identified as having either a mild ID or an ASD, iii) were able to provide informed consent. Participants

were excluded from taking part if they: i) were identified as having both ASD and ID and/or ii) had a severe visual or hearing impairment which would make it difficult for them to engage with the materials.

There were considerable difficulties in attempting to recruit participants with intellectual disabilities because the Schools and Colleges attempt to meet the support needs of their pupils and students without necessarily labelling their particular difficulties. Therefore, the diagnostic terms "Intellectual Disability" or "Learning Disability" were not widely used in schools and colleges. This meant that the researcher had to explain the recruitment criteria to staff who were asked to identify individuals they thought would be suitable for the study. However, it was apparent that the staff had difficulty differentiating between those with mild and those with borderline disabilities. Consequently, a decision was made to include participants with mild to borderline intellectual disabilities, as they were considered to belong to the intellectually disabled group in the school and college settings and were treated as members of this group.

## **Design**

A between groups comparison design was used to examine the experience of stigma of people with ASD in relation to those with ID, and to examine whether the nature of their social comparisons were similar to those with ID.

## **Measures**

The following measures were presented to the participants in the order shown below, in order to obtain background socio-demographic information and to address the research questions:

**Socio-demographic information Sheet.** Information was gathered regarding the participants' age, gender and socio-economic status. Socio-economic status was determined

using the Scottish Index of Multiple Deprivation. The scores used allowed a person's status to be rated on a scale of 1-20 based on their postcode. A score of 1 indicated the most deprived level and a score of 20 the least deprived level.

**Social comparison Scale (Dagnan and Sandhu, 1999).** The Adapted Social Comparison Scale (Dagnan and Sandhu, 1999; MacMahon and Jahoda, 2008) examines how individuals with ID evaluate themselves through their comparisons with others. The scale has three subscales, concerning how people compare themselves with others in relation to 'rank and achievement', 'social attractiveness' and 'perceived group membership' and has been found to have good internal reliability with a Cronbach alpha value of 0.72 (MacMahon and Jahoda, 2008).

Participants in this study were asked to compare themselves with: (1) a peer with evidence of significant developmental disability; and (2) a typically developing peer. *Condition (1):* Participants were read aloud a vignette describing a sixteen year old young man with a developmental disability, demonstrated by the fact that he requires help to get ready for school in the morning, his mother helps him to organise his clothes and makes his breakfast, he doesn't travel to school alone like his younger sibling, he has a helper that attends classes with him to assist him and he often spends his breaks in the support base. *Condition (2):* the same procedure was followed with a second vignette describing typically developing peer who gets himself up for school in the morning, who helps to prepare his own breakfast and who spends his break-times with his friends. The order in which the vignettes were administered was altered for consecutive participants in each group. For participants recruited from colleges, the vignette was adapted to describe a peer who was attending college.

After being presented with each vignette, participants were asked to compare themselves with the target character using a series of incomplete sentence ("When I am



with people like [character] I generally feel”) followed by a series of bipolar constructs (worse than other people/ better than other people, not as good at things/better at things, less friendly/more friendly, less shy/more shy, on your own/joined in). A visual analogue scale depicting boxes of increasing size was used across all measures to elicit participants’ levels of agreement. The only exception was the item “on your own/joined in” on the social comparison scale, which was presented using a visual analogue scale depicting a 12.5cm rectangle divided into five 2.5cm sections. Each item was presented in large print on a single, landscape-format A 4 page, the question was read aloud and participants were asked to point to the point on the scale that best represented their response. In the current study, the Social Comparison scale was found to have a Cronbach alpha value of 0.71, when participants were asked to make a comparison to a non-disabled peer, indicating acceptable internal consistency. When participants completed the scale comparing themselves to a developmentally disabled peer a less reliable Cronbach alpha value of 0.632 was obtained, indicating questionable internal consistency.

**Experience of Stigma Checklist (ESC; Cooney et al., 2006).** This is a 13-item self-report scale (Appendix 2.2). Eight items concern the frequency with which participants experience stigmatised treatment from key figures in their lives (parents, teachers, school pupils, and people in the local area). Stigma items are further split between the two themes of having been ‘made fun of’ (e.g. ‘have teachers ever made fun of you?’) and being ‘treated differently’ (e.g. Have other pupils in the school ever made fun of you?’ The items presented in each sub-scale are interspersed with positive items to help prevent the participants becoming caught in a negative response set.

The participants are asked to indicate the frequency of each experience on a five point scale (‘never, once or twice, sometimes, often, and a lot). The ESC has been found to have an alpha value of 0.61 (Cooney et al., 2006). The current study found a similar Cronbach alpha value of 0.63 indicating that the scale had limited validity.

In order to ensure that the participants' responses concerned stigmatising incidents, a sub-sample of participants were asked to provide examples of the experiences of stigma they reported. Participants' responses were recorded using a digital voice recorder and transcribed for subsequent analysis. Examples of stigma were gathered from 10 participants in the ASD group (66.7%) and for 13 participants in the ID group (65%). The examples provided by the participants were categorised as either stigmatising or non-stigmatising by an independent rater. This qualitative data also offered insight into the types of experiences described by the participants with borderline/mild ID and the participants with ASD.

**Rosenberg Self Esteem Scale (Dagnan and Sandhu, 1999).** This is a 6 item measure of self-esteem with a two factor structure (Appendix 2.3). The first factor consists of four positive self-esteem items and the second factor consists of two negative self-esteem items. Each item is a statement with which participants are asked to state their level of agreement using a visual analogue scale. The scale ranged from 'never true', 'hardly ever true', 'sometimes true', and 'often true' to 'always true'. In the current study the Cronbach alpha value was found to be 0.74, indicating an acceptable level of internal consistency.

**Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999).** This a brief measure of cognitive functioning. The WASI was used to confirm the suitability of participants within each group following recruitment and interview. In order to minimise the administration time the shorter two-subtest version of the scale was used. This version uses Vocabulary and Matrix Reasoning subtests to provide an estimate of overall full-scale IQ. The average reliability coefficient of the WASI is 0.98-0.96. Test retest reliability is 0.92 - 0.88. Inter-rater reliability is 0.98 for vocabulary and 0.99 for similarities.

## **Procedure**

In order to try and meet a suitable number of participants, six mainstream secondary schools, and one Additional Support Needs school, based in the Highlands of Scotland were

contacted. One school declined to take part. Two Highland colleges were also approached and agreed to take part. A further three colleges in Glasgow were contacted but declined to take part. An application was also made to the Glasgow Education Authority requesting consent to contact schools in Glasgow. However this application was rejected due to concerns about identifying young people with intellectual disabilities and autism. Finally, eight voluntary organisations providing support to individuals with ASD in Glasgow and Inverness were also contacted. Two of these organisations agreed to take part, although participants were only successfully recruited from one of them.

Senior staff in the schools, colleges and voluntary organisations were asked to identify young people with autism or who they believed had a mild to moderate intellectual disability. Where possible, the researcher met with groups of participants to provide information about the study. Otherwise, information sheets (Appendix 2.4), were given to potential participants by teachers or lecturers, on behalf of the researcher. The researcher then met with individuals who expressed an interest in taking part in the study and completed consent forms (Appendix 2.5) with them.

The researcher met with the participants to complete the scales and measure in a private room at the participant's school or college. The sessions lasted for approximately 45 minutes. Meetings with those recruited from the Glasgow based ASD voluntary organisation took place at the organisation's base, which these participants were familiar with. Care was taken to put the participants at their ease at the outset and to adopt a conversational tone. All the items from the measures were read out to the participants and it was made clear to them that their views were valued. A semi-structured interview approach was used with the subsample of participant's who were asked to provide examples of their experiences. The responses of this subsample were audio recorded and transcribed verbatim. The WASI is a test involving right and wrong answers and is therefore not in keeping with other measures. For this reason the WASI was completed last.

## **Justification of sample size**

As no previous studies have compared social comparison, self-esteem and stigma between young people with ASD or ID, a sample size calculation was made using a medium effect size. A calculation made using the G Power software package (Faul et al. 2007), with a power level of 0.50 at the 5% level of significance, for a two tailed between groups t-test indicated that 105 participants would be required for each group to ensure power was met. However, as the study was exploratory and involved recruiting participants from hard to reach populations, it was decided to aim to recruit 25 participants in each group. Unfortunately, the target sample size was not met due to the considerable difficulties found in identifying suitable participants. The fact that the study sought to recruit adolescents at the stage of transition also meant that a number of potential participants were lost because they left school before the term officially ended.

## **Ethical approval**

Ethical approval for the project was received from the University of Glasgow College of Medical, Veterinary and Life Sciences (MVLS) Ethics Panel. A copy of the approval letter can be found in Appendix 2.6. Additional approvals were gained from Highland Education Department and Colleges and support organisations who participated in the study.

## **Results**

Prior to data analysis, variables for the -ASD group and the borderline/mild ID group were evaluated through tests of skewness, normality of distribution and kurtosis, to determine whether the assumptions for parametric testing were met. Due to the limited sample size Shapiro-Wilk tests were used to indicate normality of distribution. Non-parametric tests of statistical significance were used when results indicated that data were not normally distributed. Independent samples t-tests were used to compare the groups

when variables did meet parametric assumptions. Two-tailed statistical tests were used due to the exploratory nature of the study. However, despite the use of multiple comparisons, Bonferroni tests were not used due to the increased risk of type-II error.

The first section below outlines participant characteristics and socio-demographic factors. This is followed by qualitative data relating to experiences of stigma, gathered from a subsample of participants from each group, and data concerning the two groups' reported experiences of stigma and their self-esteem scores. The next section presents and analyses the two groups' social comparison scores, in relation to a developmentally disabled peer and a typically developing peer. A final section describes a post-hoc analysis of social comparison scores in relation to self-esteem scores.

## **Participant and Socio-demographic details**

Following data collection, three individuals recruited to the borderline/mild ID group were excluded as their estimated IQ fell above 85 on the WASI, indicating that they did not have a borderline/mild ID. One participant was excluded from the ASD group due to the fact that they had difficulty understanding key concepts on the stigma scale meaning that their responses could not be considered reliable. Consequently, data were included for 20 young people identified as having an ID and 15 young people identified as having ASD (without ID). Table 1 shows the participant characteristics and socio-demographic data for the borderline/mild ID and ASD groups. Although a significantly greater number of participants in the ID group were recruited from colleges, the groups were well matched in terms of age, gender and deprivation scores. The Scottish Index of Multiple Deprivation scores range from 1-20 in terms of most deprived to least deprived. Therefore while participants in both groups came from a wide range of backgrounds, the mean scores for both groups were slightly above the mid-point, indicating relatively low deprivation.

The fact that individuals with IQ scores up to 85 were included in the borderline/mild ID group meant that there was some overlap between the groups in terms of their WASI IQ scores. Five participants in the ASD group had scores below 85 (range 71-82). However the mean IQ of the ASD group was significantly higher than that of the borderline/mild ID group ( $t(33)=5.405, p=0.00$ ).

Table 1

*Participant Characteristics*

| <u>Socio-demographic data</u> |            | <u>ASD Group</u> | <u>ID group</u> |
|-------------------------------|------------|------------------|-----------------|
| Gender                        | Male       | 12               | 12              |
|                               | Female     | 3                | 8               |
| Age                           | Mean (SD)  | 17.07 (1.75)     | 17.95 (1.64)    |
|                               | Range      | 16-21            | 16-21           |
| Recruitment source            | School     | 12               | 8               |
|                               | College    | 3                | 12              |
| Current education setting     | Mainstream | 13               | 16              |
|                               | Segregated | 2                | 4               |
| Living with parents           | Home       | 14               | 18              |
|                               | Away       | 1                | 2               |
| Scottish Index of Multiple    | Median     | 12.00            | 11.50           |
| Deprivation vigintile         | Range      | 2-20             | 3-19            |
| WASI IQ                       | Mean (SD)  | 93.07 (17.78)    | 69.20 (10.27)   |

*\*ASD= Autistic Spectrum Disorder, ID= Intellectual Disability*

## **Experiences of Stigma**

The Experience of Stigma Checklist (ESC) was scored on a five point Likert scale ranging from 0-4 with a score of 0 indicating no reported experience of stigma. Therefore the maximum possible score on either the "made fun of" or "treated differently" subscales was 16. A subsample of 10 ASD participants and 13 borderline/mild ID participants were asked to provide examples to justify their responses. These examples were used to assess how reliably participants reported their experiences of stigma on the measure, and provided

examples of the types of stigma described by both groups. Although the main hypothesis concerning stigma is related to the frequency of stigma experienced by each group, the content of subjects' responses on the scale were examined to ensure that they actually reflected stigma experiences.

**Reliability of participants' responses on the stigma measure.** The examples of stigma, which were provided by a subsample of participants from each group, were categorised using a directed content analysis approach (Hsieh & Shannon, 2005). The coding system of Cooney et al. (2006) was adapted for the current analysis.

The following themes were taken from Cooney et al. (2006): "being called names", "being ridiculed", "being ignored", "violent physical contact", "parents restricting", "being refused help", and "being given unwanted help". In order to conduct the content analysis, responses to items were initially categorised according to the methods of Cooney et al. (2006), new themes that did not fit with the existing categories were then examined and themes that were not used were removed. The theme of "teachers being angry about mistakes" was removed as no participants described having had this experience. The theme of "being ignored" was modified to "being ignored/excluded" when related to experiences of being made fun of, and to "being ignored/refused help" when related to being treated differently, as these themes were connected in the participants' responses.

In order to ensure that the examples provided by participants related to stigma experiences, each reported experience of stigma was independently rated, by the main researcher and a Clinical Psychologist, who had been given guidance about what constituted stigmatised treatment, to determine whether the examples could be categorised as stigma experiences. Agreement between the two raters was strong ( $K=0.95$ ) in relation to examples on the "made fun of" subscale.

Unexpectedly a number of non-stigmatising experiences were reported by participants in relation to the subscale questions regarding experiences of receiving different treatment to peers. Eight non-stigmatising experiences of “being treated differently” were described by the ASD group and three were reported by the mild/borderline ID group. Consequently, it was decided to remove the ‘treated differently’ subscale scores from the quantitative analyses as the scores did not reliably record experiences of stigma. A description of the data collected from the subsample is described in more detail below. For the ASD group the eight responses of positive experiences constituted 20% of the total number of responses, whereas for the ID group, “positive examples” represented 6% of the total responses.



**Stigma examples provided by a subsample from each group.** Table 2 shows the types of experience reported by the sub sample of participants in each group in relation to being made fun of.

Table 2  
*Subsample responses for items relating to 'being made fun of'*

| ASD group                      |                |              |                  |                |              |
|--------------------------------|----------------|--------------|------------------|----------------|--------------|
| Experience type                | Stigma source  |              |                  |                |              |
|                                | <u>Teacher</u> | <u>Pupil</u> | <u>Community</u> | <u>Parents</u> | <u>Total</u> |
| Ridiculed/called names         | 3              | 10           | 5                | 4              | 22           |
| Violent physical confrontation | 0              | 1            | 0                | 0              | 1            |
| Ignored/excluded               | 0              | 1            | 0                | 0              | 1            |
| No experience                  | 8              | 0            | 6                | 7              | 21           |
| ID group                       |                |              |                  |                |              |
| Experience type                | Stigma source  |              |                  |                |              |
|                                | <u>Teacher</u> | <u>Pupil</u> | <u>Community</u> | <u>Parents</u> | <u>Total</u> |
| Ridiculed/called names         | 3              | 8            | 3                | 3              | 17           |
| Violent physical confrontation | 0              | 0            | 0                | 0              | 0            |
| Ignored/excluded               | 0              | 2            | 0                | 1              | 3            |
| No experience                  | 10             | 4            | 10               | 9              | 33           |

*\*ID= Intellectual Disability, ASD= Autistic Spectrum Disorder. The format of questions involved asking whether participants had been made fun of by a teacher pupil, a person in the community or by their parents.*

Although there were more participants in the borderline/mild ID group, the groups reported similar numbers of experience of "being made fun of". The most common experience described by both groups was being ridiculed or called names by peers:

*"When I was first college I was doing (previous course) and I used to get bullied a lot...just got made fun of, picked on just made to feel like I was different."* (Female from the mild/borderline ID group)

*'Quite a lot of people would often be quite verbally abusive about some of my perceived physical tics or ways of speaking or anything like that.'* (Male from the ASD group)

Although it was the least reported experience, it was striking that a small number of participants in each group reported having been made fun of by teachers:

*'...I couldn't see the board and certain noises annoy me and stuff like an autistic thing, and then this teacher was like 'oh have you took your meds yet?'* (Male in the ASD group)

*'Em, we were stood round the place at break time and one of the lecturers came and said 'oh you look like losers stood there'.* (Male in the mild/borderline ID group)

**Reports of Being Treated Differently.** Table 3 shows the types of experience reported by the sub sample of participants who were asked to give examples of such treatment.

Table 3  
*Subsample responses for items relating to 'being treated differently'*

| ASD group              |                |              |                  |                |              |
|------------------------|----------------|--------------|------------------|----------------|--------------|
| Experience type        | Stigma source  |              |                  |                |              |
|                        | <u>Teacher</u> | <u>Pupil</u> | <u>Community</u> | <u>Parents</u> | <u>Total</u> |
| <u>Stigma</u>          |                |              |                  |                |              |
| Ridiculed/called names | 0              | 1            | 1                | 0              | 2            |
| Ignored/refused help   | 0              | 1            | 0                | 0              | 1            |
| Parents restricting    | 0              | 0            | 0                | 1              | 1            |
| Unwanted help          | 2              | 2            | 0                | 0              | 4            |
| Unable to give example | 0              | 1            | 0                | 0              | 1            |
| <u>Non-stigma</u>      |                |              |                  |                |              |
| No experience          | 4              | 4            | 8                | 6              | 22           |
| Positive experience    | 3              | 1            | 1                | 3              | 8            |
| ID group               |                |              |                  |                |              |
| Experience type        | Stigma source  |              |                  |                |              |
|                        | <u>Teacher</u> | <u>Pupil</u> | <u>Community</u> | <u>Parents</u> | <u>Total</u> |
| <u>Stigma</u>          |                |              |                  |                |              |
| Ridiculed/called names | 2              | 3            | 4                | 1              | 10           |
| Ignored/refused help   | 2              | 3            | 1                | 0              | 6            |
| Parents restricting    | 0              | 0            | 0                | 5              | 5            |
| Unwanted help          | 1              | 0            | 0                | 0              | 1            |
| Unable to give example | 0              | 0            | 1                | 0              | 1            |
| <u>Non-Stigma</u>      |                |              |                  |                |              |
| No experience          | 4              | 7            | 7                | 8              | 26           |
| Positive experience    | 2              | 1            | 0                | 0              | 3            |

*\*ID= Intellectual Disability, ASD= Autistic Spectrum Disorder. The format of questions involved asking whether participants had been made fun of by a teacher pupil, a person in the community or by their parents.*

For both groups positive examples involved others responding to their level of ability:

*'Yeah 'cause I get special other stuff... other things other subjects different ones that are easier.'* (Female from the borderline/mild ID group)

*'...Like getting special needs support or like teachers doing progress reviews and stuff like asking how you're getting on.'* (Male in the ASD group)

*'I suppose they see me as someone they could ask quite quickly for answers 'cos I've done quite well in the past. So it wasn't you know in a bad way they treated me like I was quite intelligent which was actually a good thing.'* (Male in the ASD group)

Despite a number of participants reporting positive experiences of being treated differently, 78% of the examples provided by the ASD group, and 90% of examples provided by the borderline/mild ID group, appeared to describe stigmatised treatment. Participants in the ASD group reported fewer examples of being treated differently across all items. Illustrative examples of reported experiences are shown below.

Examples of being made fun of:

*'Em there's some people who will say "oh you're immature" and all that but you're not really.'* (Female from the mild/borderline ID group)

*'you're going to be treated differently to their friends and that because it's kind of how the pecking order works...verbal insults and you walk past and they all stare at you and start laughing.'* (Male from the ASD group)

Examples relating to being ignored or refused help included:

*'I, em was out with a friend and she... saw another friend... she was treating me as though I wasn't there.'* (Female from the ID group)

*'I think they just thought I was weird and they didn't really like me and you know... just kind of none of them would talk to me...'* (Female from the ASD group)

Participants in both groups expressed concern about facing restrictions from their parents. However, the example from the participant in the ASD group related to a more general feeling of restriction and was less clear:

*'They don't let me do... They wouldn't let me stay out late and stuff.'* (Male from the borderline/mild ID group)

*'Overprotective...because they know I can't really do things myself.'* (Female from the borderline/mild ASD group)

Although reported by one participant in the borderline/mild ID group, examples of feeling stigmatised by receiving unwanted help were more frequently reported by participants in the ASD group. Many of the examples provided indicated that participants were sensitive to the timing or delivery of support that made the experience feel negative.

*'...it's like they're always asking if I need help for anything like they're overdoing it on giving me help for my disability, like if I needed it I'd ask for it.'* (Male from the ASD group)

*'When it comes to taking the notes in history the teacher will print them off 'cos she knows I have to keep looking at the board for the spellings...and she always turns round and everyone hears her say {name} I'm going to print this off and everyone hears her and then people get annoyed'* (Female from the ID group)

The example provided by one male participant from the ASD group captured how complex it might be to provide support to individuals:

*'it didn't really help that I was singled out from the rest like every teacher was like {name} "do you need any help with your work, do you need help writing, do you need to go for a walk and calm down" and I'm like "no just leave me alone" so they were probably trying to be helpful it was just wrong time wrong place to be helpful'*

**Hypothesis 1: Individuals with ASD will be less aware of experiencing stigma than those with ID.** As the subscale relating to 'being treated differently' was not found to consistently relate to stigmatising experiences, only results for the 'made fun of' subscale were included within the analyses. Table 4 shows the mean scores and numbers of participants reporting experiences of stigma in relation to being made fun of.

Table 4  
*Experience of Stigma Scale subscale mean scores for participants reporting experiences of 'being made fun of'*

| <u>Stigma Source</u> | <u>Mean (SD)</u> |             | <u>N reporting experience</u> |           |
|----------------------|------------------|-------------|-------------------------------|-----------|
|                      | <u>ASD</u>       | <u>ID</u>   | <u>ASD</u>                    | <u>ID</u> |
| Teacher              | 1.25 (0.5)       | 2.50 (2.12) | 4                             | 2         |
| Pupils               | 2.15 (0.80)      | 2.08 (1.12) | 13                            | 13        |
| Community            | 1.60 (0.55)      | 2.60 (1.34) | 5                             | 5         |
| Family               | 1.63 (1.06)      | 1.75 (0.89) | 8                             | 8         |
| Total                | 6.63 (2.91)      | 8.93 (5.47) |                               |           |

*\*ASD= Autistic Spectrum Disorder, ID=intellectual Disability, SD=Standard Deviation. Mean scores were produced from the results of individuals providing positive responses. Items were scored on a scale of 0-4 from "No experience" to "A lot of experience" of the type of stigma being examined.*

Results indicated that the mean scores for participants in the ID group were higher in relation to being made fun of by teachers, people in the community and family members. Whereas, participants with ASD reported slightly higher mean scores in relation to being made fun of by other pupils. Combined total mean scores were higher for the ID group, however there was also greater variance in scores for the ID group. Overall, 18 (90%)

participants in the borderline/mild ID group reported being made fun of compared to 14 (93.3%) participants in the ASD group.

A Mann-Whitney U test was used to assess whether there were significant differences between the ASD group and the borderline/mild ID group in terms of their scores on the “made fun” of stigma subscale. The result indicated that there were no significant differences between the groups ( $U=115$ ,  $p=0.24$ ,  $r=0.20$ ). Therefore, the hypothesis that individuals with ASD would be less aware of experiencing stigma than those with ID was not supported, as similar numbers of participants in each group reported experiences of “being made fun of” and no significant difference was found in the reported severity of stigma experience for each group.

## **Self-Esteem Scores**

**Hypothesis 2: Individuals with ASD will have higher self-esteem than those with ID.** The maximum possible on the Adapted Rosenberg Self-esteem Scale, indicating high self-esteem, was 30. For the positive and negative subscales the maximum possible scores were 20 and 10 respectively. As shown in Table 5, both subscale scores and total scores indicate that the mean scores of participants in both groups indicated positive self-esteem. Norms were not available for the adapted Rosenberg Self-Esteem scale with non-ID populations, however the scores obtained in the current study were lower than those found within an adult ID population in a similar study (Paterson et al., 2012).

Table 5 shows that the mean total scores were similar for both the ID and ASD group, as were mean scores on both positive and negative subscales. An independent samples t-test confirmed that there were no significant differences between the ID and ASD groups in terms of overall Self-esteem scores,  $t(33)=-0.178$  ( $p=8.68$ ). Therefore, the

hypothesis that individuals with ASD would have significantly higher self-esteem scores was not supported.

Table 5  
*Rosenberg Self-esteem Scale (SE) subscale and total scores for each group*

| SE Subscale    | Mean (SD) by group |              |
|----------------|--------------------|--------------|
|                | <u>ASD</u>         | <u>ID</u>    |
| Positive       | 14.07 (2.81)       | 14.60 (3.45) |
| Negative       | 7.40 (1.76)        | 7.10 (4.32)  |
| Combined total | 21.47 (4.32)       | 21.70 (3.42) |

*\*ASD= Autistic Spectrum Disorder, ID= Intellectual Disability. Higher scores indicate more positive self-esteem. The maximum possible score was 20 for the positive items which demonstrated agreement with a positive statement about self-esteem and the maximum possible score for negative items was 10, indicating disagreement with a negative statement about the self.*

**Hypothesis 3: Reported stigma scores will be negatively associated with self-esteem scores for both groups.** A Spearman's correlation was carried out to examine the possible association between scores on the self-esteem scale and the "Being made fun of" stigma subscale, for both groups. No significant association between scores was found for the ASD group ( $r=-0.13$ ,  $n=15$ ,  $p=0.64$ ) or the borderline/mild ID group ( $r=-0.16$ ,  $n=20$ ,  $p=0.28$ ). Therefore hypothesis 3 was not supported.



## Social Comparison Scores

**Hypothesis 4: Both groups will make significantly more positive social comparisons when comparing to a target individual with developmental delay than when comparing to a typically developing individual.** Mean

scores for the subscales on the Social Comparison Scale (SCS) for both the borderline/mild ID group and the ASD group are shown in Table 6.

Table 6  
*Social comparison scale subscale scores and totals by group*

| Vignette  | SCS Sub-scale              | Mean (SD) by group |              |          |          |
|---|----------------------------|--------------------|--------------|----------|----------|
|   |                            | <u>ASD</u>         | <u>ID</u>    | <u>Z</u> | <u>P</u> |
| Comparison to<br>Character with<br>developmental<br>delay | Rank and achievement       | 7.60 (1.45)        | 7.30 (2.08)  |          |          |
|   | Social attractiveness      | 7.87 (1.85)        | 7.81 (1.85)  |          |          |
|   | Perceived group membership | 3.20 (1.32)        | 3.80 (1.40)  |          |          |
|   | Total                      | 18.67 (3.68)       | 18.90 (3.84) | 266.0    | .89      |
| Comparison to<br>typically<br>developing<br>character     | Rank and achievement       | 6.13 (1.36)        | 6.80 (1.70)  |          |          |
|   | Social attractiveness      | 6.20 (1.78)        | 7.25 (1.86)  |          |          |
|   | Perceived group membership | 3.13 (1.30)        | 3.85 (1.39)  |          |          |
|   | Total                      | 15.47 (3.83)       | 17.90 (3.80) | 220.0    | 0.94     |

*\*ASD= Autistic Spectrum Disorder, ID= Intellectual Disability. On the 'Rank and achievement' and 'Social attractiveness' subscales a score greater than 6 indicated a positive comparison and for the 'Perceived group membership' a score greater than 3 indicated a positive comparison.*

For both the borderline/mild ID group and the ASD group, the mean scores on the social comparison scale were positive, indicating that they viewed themselves favourably, whether they were comparing themselves to an individual with developmental delay or a typically developing individual. The total mean scores of both groups were higher when participants compared themselves to an individual with developmental delay than when

comparing themselves to a typically developing individual. However, the difference was only significant for the ASD group ( $Z=-2.70$ ,  $p=0.007$ ). The difference in scores was not significant for the borderline/mild ID group ( $Z=1.39$ ,  $p=0.166$ ). Consequently, the hypothesis that there would be a significant difference between how the participants compared themselves with an individual with a developmental delay and a typically developing individual was only upheld for the ASD group. Unexpectedly, the reason for the significant difference in the ASD group's comparisons was because they viewed themselves less positively in relation to the typically functioning individual than the ID group.

## Post hoc analysis

### **Hypothesis 5: For both groups, self-esteem will be positively associated**

**with more positive social comparisons when comparing to others.** For each

group, Spearman's correlations were carried out between self-esteem scores and social comparison scores in relation to the two social comparison scores. Table 7 shows the association between scores on the self-esteem scale and scores on the two versions of the social comparison scale. For the ASD group, self-esteem scores were positively correlated with social comparison scale scores when comparing to either an individual with a developmental disability or a typically developing individual. No association was found for the borderline/mild ID group. Thus, the hypothesis that higher self-esteem would be positively associated with positive social comparison was supported for the ASD group only.

Table 7

*Association between Rosenberg self-esteem scale scores and social comparison scale scores*

| SCS version                                      | Participant Group |                    |
|--|-------------------|--------------------|
|  | <u>ASD</u>        | <u>ID</u>          |
| Comparison to typically developing character     | $r=0.51, p=0.05$  | $r=0.387, p=0.092$ |
| Comparison to Character with developmental delay | $r=0.66, p=0.007$ | $r=0.31, p=0.18$   |

*\*ASD= Autistic Spectrum Disorder, ID= Intellectual Disability.*

## Discussion

The current study has demonstrated that young people with Autistic Spectrum Disorder (ASD) are able to describe experiences of stigma. The study has also shown that

young people with ASD are able to compare themselves differently to members of different target groups. These findings suggest that, despite their social cognitive deficits, individuals with ASD might develop a sense of self using similar social processes as other individuals.

It has been proposed that one way in which individuals develop a sense of self within a social context is by observing how other individuals respond to their actions (Cooley, 1902), and by taking on the perspectives of others (Mead, 1934). As young people with ASD are known to be at greater risk of experiencing bullying (Little, 2002) and stigma (Staniland and Byrne, 2013) it is possible that their devalued status may have implications for their sense of self. However, it might be expected that the social cognitive difficulties which characterise ASD could impact on how the self-views of individuals with ASD are affected by experiencing a devalued social status. As the current study has demonstrated that young people with ASD are capable of recognising and describing experiences of stigma, it remains possible that their awareness of such experiences may have an impact on their sense of self.

Similar to Cooney et al. (2006), the present study found that young people with borderline/mild ID were also able to recognise and describe their experiences of stigma. However, the current study found more complex responses to the Experience of Stigma Checklist than previously reported. The stigma scores reported by the two groups were similar in relation to 'being made fun of', but within the subscale describing experiences of 'being treated differently', individuals with ASD reported fewer experiences than those with borderline/mild ID. Interestingly, the ASD group were also more likely to report non-stigmatising experiences of 'being treated differently'. Individuals with ASD might experience difficulty in recognising when they were being 'treated differently', perhaps because this often requires an ability to have insight into the other person's intentions. As the wording of items relating to 'being treated differently' was potentially ambiguous, due to the fact that negative experiences were not explicitly asked about, the positive responses do

not necessarily indicate that participants with ASD have difficulty understanding the concept of being treated differently to others. It is possible that difference in response patterns between the two groups, in relation to stigma, could be due to the fact that participants with ASD interpreted the question in a more concrete way, whilst those with borderline/mild ID were more likely to infer from the context of the other questions that negative experiences were being enquired about. However, it is also possible that the difference in responses may simply be a reflection of the fact that individuals with ASD had more positive experiences of being treated differently than the borderline/mild ID group did.

Although the ASD group reported fewer overall experiences of being treated differently, the most commonly reported example for this group was related to being given unwanted help. The examples provided suggested that individuals could recognise that the intentions of others were likely to have been well meaning, yet were not experienced as being helpful for participants. At the very least, the evidence suggests that some individuals with ASD are sensitive to being treated differently and are able to consider the intentions of other individuals. It also suggests that whilst individuals with ASD recognise a need for help, they may be sensitive to how or when it is delivered.

As has been discussed, experiences of stigma are important due to the potential impact of stigma on individuals self-views. Social comparison theory (Festinger, 1954) is proposed as a possible mechanism by which individuals can mediate the impact of stigma on their sense of self. As with theories of the self, social comparison requires sufficient social understanding for an individual to be able to compare their own characteristics to those of another individual, and make positive or negative comparisons about themselves. The current study found that individuals with ASD are capable of making different comparisons depending on who they compare themselves with. Although this does not necessarily mean that individuals with ASD make use of social comparison to maintain a positive sense of self

in the face of stigma, it does suggest that they have the ability to make positive social comparisons which could protect their sense of self.

Previous research has also shown that individuals with intellectual disabilities are able to make different social comparisons with disabled and non-disabled individuals, supporting the idea that social comparisons may serve to protect self-esteem (Cooney et al., 2006; Paterson et al., 2012). The current study found that participants with ASD viewed themselves less positively in relation to a typically developing target, than when comparing to a developmentally disabled target. Although the same direction of difference in scores was found for the borderline/mild ID group, it was not significant. Therefore it appears that individuals with ASD viewed their own abilities less positively in relation to a typically developing individual than did individuals with borderline/mild ASD.

As the social comparison scale consisted of a bipolar constructs, it might be expected that participants with ASD would provide answers more at the extremes of the scale. However, this was not indicated as comparison scores were positive regardless of the target being compared to. It is possible that individuals with borderline/mild ASD spent less time in mainstream classes than those with ASD due to the differences in the academic ability between the groups, i.e. individuals with intellectual disabilities may require more time receiving support apart from their mainstream peers. It is therefore possible that far from being unable to make social comparisons, participants in the ASD group may have been more socially aware than participants in the borderline/mild ID group. As the process of recruitment within the current study demonstrated that the term 'Intellectual Disability' was used less frequently than 'Autistic Spectrum Disorder' it may be that the ASD group experienced higher levels of labelling. However, evidence shows that labelling may have both a positive (Farrugia, 2009) and negative impact (Link and Phelan, 2001).

As individuals with ASD viewed themselves less positively in relation to typically developing individuals, it is possible that their comparisons could have important implications in relation to their sense of self. The fact that a relationship was found between positive self-esteem and positive social comparison scores also supports the possibility that the comparisons individuals made related to how they felt about themselves. Although it is not possible to state whether social comparisons have an impact on self-esteem for individuals with ASD, these results suggest that it is possible that individuals with ASD, who do not have intellectual disabilities, may develop a sense of self in a similar way to other individuals.

The current study has demonstrated that a group of individuals with ASD were capable of recognising and describing experiences of stigma. Although there were some differences in the experiences reported by the two groups, it is unclear whether this was a reflection of the fact that the two groups had different experiences, or if it was due to differences in how individuals with ASD or borderline/mild ID understood and interpreted experiences. Unexpectedly, the ASD group were found to make less positive social comparisons with a typically developing peer, than the borderline/mild ID group, suggesting that they may actually have been more aware of their social position in relation to other individuals. The evidence shows that individuals with ASD are able to display some of the core abilities which are proposed as key in developing a sense of self in typically functioning and intellectually disabled populations.

## **Limitations**

The current study has several methodological limitations that require consideration. Considerable difficulties in recruitment meant that the desired sample size of 25 individuals in each group was not met. A larger sample may have allowed further relationships to emerge, such as the possible association between self-esteem and stigma experiences and

the social comparison to different peers. As individuals were included who had borderline intellectual disability, the IQ scores of 5 individuals in the ASD group overlapped with the scores of the ID group.

The Cronbach alpha values obtained for the Experience of Stigma Checklist and the social comparison scale, when participants compared to a target with a developmental disability, indicated that the internal consistency of the scales were below the desired level. A further limitation of the stigma checklist was that both groups reported non-stigmatising examples in relation to the subscale asking about experiences of being treated differently, meaning that the reliability of the subscale is in question. As has been discussed, there was some ambiguity in the wording of the question relating to 'being treated differently'. In future studies, the question could be reworded to clearly refer to experiences that were viewed negatively by the participant, e.g. "have you ever been treated differently to other young people, in a bad way".

## **Further Research**

The current research has demonstrated that young people with ASD are able to recognise and describe experiences of stigma. As they were less likely to report experiences of different treatment, further research assessing whether this is due to the fact that individuals with ASD are less likely to experience stigma in relation or if they report these experiences less frequently due to being less aware of these experiences as a result of the social cognitive difficulties associated with ASD. Further studies could examine the ability of individuals with ASD to recognise other people being treated in a stigmatised way, to assess their ability to understand the concept of being treated differently. Investigating the types of stigma experience that are most salient for individuals with ASD would assist in understanding whether they are less likely to attend to certain experiences.



A key question that the current study was not able to answer was whether individuals with ASD internalise experiences of stigma in a similar way to those who do not have ASD. As the relationship between self-esteem and stigma was not found for the borderline/mild ID group as had been reported by previous studies (Paterson et al., 2012; Szivos-bach, 1993), it is possible that further studies with larger sample sizes may be useful in exploring this possible association in groups of individuals with ASD.

The study has found evidence that young people with ASD, who do not have intellectual disabilities, are able to make different social comparisons in relation to different targets, which opens the possibility that they may use social comparison as to control the impact of stigmatising experiences. However it is not possible to assess this from the current evidence. Further studies investigating whether young people with ASD make use of social comparisons without being provided with predefined targets would be useful.

## **Clinical Implications**

It is important to understand whether being treated in a stigmatised way has similar impacts for individuals with ASD as it does for other individuals due to the greater prevalence of anxiety and depression experienced by people with ASD (Hedley & Young, 2006). It is also important to understand whether social comparisons may serve a role in maintaining a positive self-view in light of experiencing a devalued social status. The fact that young people with ASD were found to make less positive comparisons to non-disabled peers, and the fact that social comparison was related to self-esteem, suggests that they may develop self-views in a similar way to other individuals. The examples of stigma provided by individuals with ASD also demonstrated that whilst receiving assistance can be viewed positively, individuals may be sensitive to the timing and type of help that is provided.

As positive social comparisons may offer a mechanism of maintaining a positive sense of help despite experiencing a devalued status, and individuals with ASD were able to make different comparisons, it may be possible that teaching individuals with ASD to select different targets for comparison, or placing salience on different attributes, could help them to maintain a positive self-view.

## **Conclusions**

This study has offered new evidence regarding the ability of young people with ASD to recognise experiences of stigma and to make comparisons of themselves to others that involve a level of social understanding that might not be expected given the social cognitive difficulties which characterise ASD. The way in which individuals with ASD understand experiences and develop their sense of self has received very little study. The current findings suggest that whilst there may be differences in how individuals with ASD understand stigma, compared to those with borderline/mild ID, it should not be assumed that they do not have understanding of social situations, although the study did not find that stigma impacted on self-esteem. Further research is required to understand the processes through which individuals with ASD develop their sense of self.

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### **Chapter 3: Advanced Practice 1: Reflective Critical Account**

#### **Clinical Skills Development Throughout Training Utilising the Integrated Developmental Model (abstract only)**

Reflective practise is a process that allows psychologists to become increasingly self-aware. Recognising areas of strength and weakness and considering developmental needs allows psychologists to ensure that they are providing clients with good quality care. Within the current reflective account I have used Stoltenberg and Delworth's Integrated Developmental Model (1987) to reflect on my development over the course of my placement with a particular focus on how I have adapted to using a range of approaches within my clinical work. The IDM describes how the three areas of self and other awareness, motivation, and Autonomy develop over time, describing core challenges and abilities at three different levels of development. Although the model describes a linear developmental process, it describes how therapists can be working at different developmental stages in relation to different domains of professional ability.

Within the current account, I describe how I have used the Integrated Developmental Model has helped me to reflect on and understand my experiences throughout placement. The process of recognising the challenges faced by trainees as they transition to different levels of development has allowed me to normalise my experiences and to consider my developmental needs as I develop my clinical skills. I have also considered how my developmental level has impacted on my experiences within supervision, and how I can use these reflections to change my future practice.

I have concluded with a reflection on the experience of developing the current reflective account and how I have used this process to shape my practise.

## **Chapter 4: Advanced Practice 2: Reflective Critical Account**

Development of Leadership Skills: reflections on the developing role of psychologists and opportunities to demonstrate leadership within training

As the numbers of Clinical Psychologists has increased within the NHS, the profession has experienced greater professional recognition but also faces challenges. The importance of leadership within the profession of Clinical Psychology has received increasing attention in recent years. As a highly trained professional group it is essential that psychologists are aware of how their skills can contribute positively to the profession and to wider services, for example the research skills of clinical psychologists place them in a position to be able to evaluate professional practice. However leadership can also be demonstrated in a broader sense within a variety of the roles that Clinical Psychologists undertake, such as contributing to team functioning and offering consultation and supervision.

Within the current review I examine three situations where I have become aware of how I have utilised my underlying clinical skills and psychological knowledge within different professional settings that reflect the varying role of Clinical Psychologists, in particular providing different forms of consultation and supervision. All of the reflections within the current account relate to experiences that I have had within the third year of my training yet they all reflect skills that I have developed throughout my training, starting in first year.

Finally I consider the common factors between my three reflections, particularly how I have been able to transfer key skills to different settings. I also consider why it is important to continue to reflect on my progress in order to remain aware of the core skills and knowledge that underpin my practice.



## Appendix 1.1: Journal of Intellectual Disability Research Author Guidelines



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### **3.1. Getting Started**

**Content of Author Guidelines:** 1. General, 2. Ethical Guidelines, 3. Submission of Manuscripts, 4. Manuscript Types Accepted, 5. Manuscript Format and Structure, 6. After Acceptance.

**Relevant Documents:** [Colour Work Agreement Form](#)

**Useful Websites:** [Submission Site](#), [Articles published in The Journal of Intellectual Disability Research](#), [Author Services](#), [Blackwell Publishing's Ethical Guidelines](#), [Guidelines for Figures](#).

## **1. GENERAL**

*The Journal of Intellectual Disability Research* is devoted exclusively to the scientific study of intellectual disability and publishes papers reporting original observations in this field. The subject matter is broad and includes, but is not restricted to, findings from biological, educational, genetic, medical, psychiatric, psychological and sociological studies, and ethical, philosophical, and legal contributions that increase knowledge on the treatment and prevention of intellectual disability and of associated impairments and disabilities, and/or inform public policy and practice. Such reviews will normally be by invitation. The Journal also publishes Full Reports, Brief Reports, Letters to Editor, and an 'Hypothesis' papers. Submissions for Book Reviews and Announcements are also welcomed.

*The Journal of Intellectual Disability Research* will feature four Annotation articles each year covering a variety of topics of relevance to the main aims of the journal or topics. Senior researchers, academics and clinicians of recognised standing in their field will be invited to write an Annotation for the journal covering an area that will be negotiated with the Associate Editor, Prof. Chris Oliver, on behalf of the Editorial team. Anyone expert in his/her particular field wishing to submit an uninvited review is advised to seek prior guidance from the Associate Editor.

All papers are assessed by expert referees.

Please read the instructions below carefully for details on the submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication in *The Journal of Intellectual Disability Research*. Authors are encouraged to visit John Wiley & Sons Pte Ltd's [Author Services](#) for further information on the preparation and submission of articles and figures.

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### **2.1. Authorship and Acknowledgements**

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the Journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship and, except in the case of complex large-scale or multi-centre research, the number of authors should not exceed six.

*The Journal of Intellectual Disability Research* adheres to the definition of authorship set up by The International Committee of Medical Journal Editors (ICMJE). According to the ICMJE authorship criteria should be based on 1) substantial contributions to conception and design of, or acquisition of data or analysis and interpretation of data, 2) drafting the article or revising it critically for important intellectual content and 3) final approval of the version to be published. Authors should meet conditions 1, 2 and 3.

It is a requirement that all authors have been accredited as appropriate upon submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

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## 2.2. Ethical Approvals

**Experimental Subjects:** experimentation involving human subjects will only be published if such research has been conducted in full accordance with ethical principles, including the World Medical Association Declaration of Helsinki (version, 2002 [www.wma.net/e/policy/b3.htm](http://www.wma.net/e/policy/b3.htm)) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included. Editors reserve the right to reject papers if there are doubts as to whether appropriate procedures have been used.

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**Ethics of investigation:** Papers not in agreement with the guidelines of the Helsinki Declaration as revised in 1975 will not be accepted for publication.

## 2.3 Clinical Trials

**Clinical trials** should be reported using the CONSORT guidelines available at [www.consort-statement.org](http://www.consort-statement.org). A CONSORT checklist should also be included in the submission material ([http://www.consort-statement.org/mod\\_product/uploads/CONSORT\\_2001\\_checklist.doc](http://www.consort-statement.org/mod_product/uploads/CONSORT_2001_checklist.doc)).

Manuscripts reporting results from a clinical trial must provide the registration number and name of the clinical trial. Clinical trials can be registered in any of the following free, public clinical trials registries: [www.clinicaltrials.gov](http://www.clinicaltrials.gov), [clinicaltrials-dev.ifpma.org/](http://clinicaltrials-dev.ifpma.org/), [isrctn.org/](http://isrctn.org/). The clinical trial registration number and name of the trial register will be published with the paper.

*The Journal of Intellectual Disability Research* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public clinical trials registries: [www.clinicaltrials.gov](http://www.clinicaltrials.gov), [clinicaltrials-dev.ifpma.org/](http://clinicaltrials-dev.ifpma.org/), [isrctn.org/](http://isrctn.org/). The clinical trial registration number and name of the trial register will then be published with the paper.

## 2.4 Conflict of Interest and Source of Funding

**Conflict of Interest:** Authors are required to disclose any possible conflict of interest. These include financial (for example patent, ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflicts of interest) will be published under a separate heading entitled 'Conflict of Interests'.

*The Journal of Intellectual Disability Research* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflicts of interest noted. As of 1st March 2007, this information will be a requirement for all manuscripts submitted to the

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If the author does not include a conflict of interest statement in the manuscript then the following statement will be included by default: "No conflicts of interest have been declared".

**Source of Funding:** Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

## **2.5 Appeal of Decision**

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## **2.6 Permissions**

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### 3. SUBMISSION OF MANUSCRIPTS

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- If you are creating a new account.
  - After clicking on 'Create Account', enter your name and e-mail information and click 'Next'. Your e-mail information is very important.
  - Enter your institution and address information as appropriate, and then click 'Next.'
  - Enter a user ID and password of your choice (we recommend using your e-mail address as your user ID), and then select your area of expertise. Click 'Finish'.
- If you have an account, but have forgotten your log in details, go to Password Help on the journals online submission system <http://mc.manuscriptcentral.com/jidr> and enter your e-mail address. The system will send you an automatic user ID and a new temporary password.
- Log-in and select 'Author Center'.

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- Click the 'Next' button on each screen to save your work and advance to the next screen.
- You are required to upload your files.
  - Click on the 'Browse' button and locate the file on your computer.
  - Select the designation of each file in the drop-down menu next to the Browse button.
  - When you have selected all files you wish to upload, click the 'Upload Files' button.
- Review your submission (in HTML and PDF format) before sending to the Journal. Click the 'Submit' button when you are finished reviewing.

#### 3.3. Manuscript Files Accepted

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rtf) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing. The files will be automatically converted to HTML and PDF on upload and will be used for the review process. The text file must contain the entire manuscript including title page, abstract, text, references, tables, and figure legends, but no embedded figures. Figure tags should be included in the file. Manuscripts should be formatted as described in the Author Guidelines below.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx file as .doc before uploading.

### **3.4. Blinded Review**

All manuscripts submitted to The Journal of Intellectual Disability Research will be reviewed by two experts in the field. The Journal of Intellectual Disability Research uses double-blinded review. The names of the reviewers will thus not be disclosed to the author submitting a paper and the name(s) of the author(s) will not be disclosed to the reviewers.

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Please upload:

- Your manuscript without title page under the file designation 'main document'
- Figure files under the file designation 'figures'
- The title page, Acknowledgements and Conflict of Interest Statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

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The Journal of Intellectual Disability Research attempts to keep the review process as short as possible to enable rapid publication of new scientific data. In order to facilitate this process, please suggest the names and current e-mail addresses of 1 potential international reviewer whom you consider capable of reviewing your manuscript. In addition to your choice the journal editor will choose one or two reviewers as well.

### **3.6. Suspension of Submission Mid-way in the Submission Process**

You may suspend a submission at any phase before clicking the 'Submit' button and save it to submit later. The manuscript can then be located under 'Unsubmitted Manuscripts' and you can click on 'Continue Submission' to continue your submission when you choose to.

### **3.7. E-mail Confirmation of Submission**

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### 3.9. Submission of Revised Manuscripts

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## 4. MANUSCRIPT TYPES ACCEPTED

**Original Research Article** The main text should proceed through sections of Abstract, Introduction, Methods, Results, and Discussion.

**Full Reports** of up to 4,500 words are suitable for major studies, integrative reviews and presentation of related research projects or longitudinal enquiry of major theoretical and/or empirical conditions.

**Brief Reports** of up to 1,500 words are encouraged especially for replication studies, methodological research and technical contributions.

**Annotation Articles** should be no more than 5,500 words long including tables and figures and should not have been previously published or currently under review with another journal. The normal instructions to authors apply. The date for submission of the article should be negotiated with the Associate Editor. An honorarium of £400 in total shall be paid to the authors(s) when the article is accepted for publication.

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**A Hypothesis Paper** can be up to 2,500 words and no more than twenty key references. It aims to outline a significant advance in thinking that is testable and which challenges previously held concepts and theoretical perspectives.

## 5. MANUSCRIPT FORMAT AND STRUCTURE

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## 5.2. Structure

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**Title Page:** Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process.**

However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

**Keywords:** The author should also provide up to six keywords to aid indexing.

**Abstracts:** For full and brief reports a structured summary should be included at the beginning of each article, incorporating the following headings: **Background, Method, Results, and Conclusions.** These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

**Optimizing Your Abstract for Search Engines:** Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimizing your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled [these guidelines](#) to enable you to maximize the web-friendliness of the most public part of your article.

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The Journal follows the Harvard reference style. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood.
- Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* **24**, 137- 41.



- Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3–18. American Association on Mental Retardation, Washington, DC.

Where more than six authors are listed for a reference please use the first six then 'et al.'

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#### **5.4. Tables, Figures**

**Tables:** Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc., and give a short caption.

**Figures:** All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained.

Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

#### **Preparation of Electronic Figure for Publication**

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**Figure Legends:** In the full-text online edition of the Journal, figure

## Appendix 1.2: Adapted checklist for case series studies

| <b>Study Objective</b>   | yes  | Unclear | No  |
|--|------|---------|-----|
| 1. Is the hypothesis/aim/objective of the study stated clearly in the abstract, introduction, or methods section?  |      |         |     |
| <b>Study Population</b>  |      |         |     |
| 2. Was a standardised anxiety measure used in inclusion?   |      |         |     |
| 3. Was a standardised measure of IQ used in inclusion?   |      |         |     |
| <b>Intervention</b>  |      |         |     |
| 4. Was the intervention clearly described in the study?  |      |         |     |
| 5. Were suitable measures of fidelity used?  |      |         |     |
| <b>Outcome measure</b>   |      |         |     |
| 6. Were relevant outcomes appropriately measured with objective and/or subjective methods?   |      |         |     |
| 7. Were the relevant outcomes assessed blinded to intervention status or group?  |      |         |     |
| <b>Statistical analysis</b>  |      |         |     |
| 8. Were the statistical tests used to assess the relevant outcomes appropriate?  |      |         |     |
| <b>Results and conclusions</b>   |      |         |     |
| 9. Does the study provide estimates of the random variability in the data analysis of relevant outcomes (e.g. standard error, standard deviation, confidence interval for all relevant primary and secondary outcomes? |      |         |     |
| 10. Are the conclusions of the study supported by results?   |      |         |     |
| <b>Competing interests and sources of support</b>  |      |         |     |
| 11. Are both competing interests and sources of support for the study reported   |      |         |     |
| <b>Overall evaluation of study design and implementation</b>   | (++) | (+)     | (-) |
| <b>(A)</b> Randomised control trial  |      |         |     |
| <b>(B)</b> Non Randomised control Trial  |      |         |     |
| <b>(C)</b> Case Series   |      |         |     |

## Appendix 2.1: Social Comparison Scale Vignettes and items

### Developmentally delayed peer

George is 16 years old. George needs lots of help to get ready for school in the morning. His mum lays his clothes out for him and makes his breakfast. George doesn't travel to school alone like his younger brother. Instead someone takes him to make sure he's OK.

When he is at school, George has a helper that goes to every class with him to make sure he's OK. George often spends his breaks in the support base.

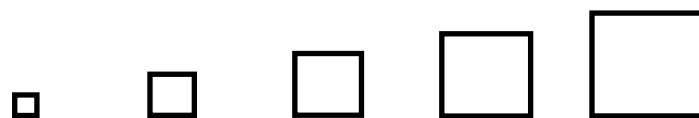
### Typically developing peer

Billy is 16 years old. Billy gets himself up for school in the morning, and usually helps to make his own breakfast. Billy goes to school on the bus with other pupils from his school.

Billy gets on with his work at school and spends his break times with his friends.

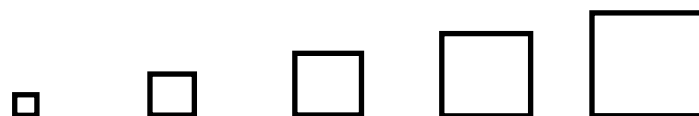
Worse than other people

Better than other people



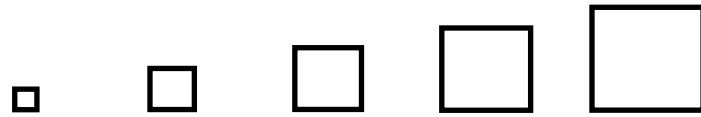
Not as good at things

Better at things



Less friendly

More friendly



Less shy

More shy



On your own

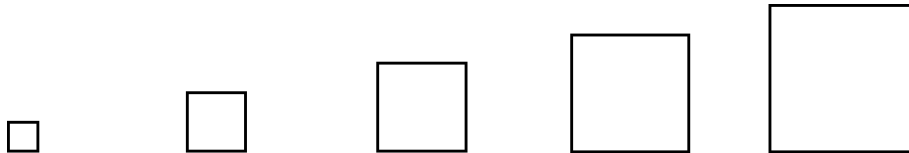
Joined in

|  |  |  |  |  |
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## Appendix 2.2: Experience of Stigma Scale

### Question 1

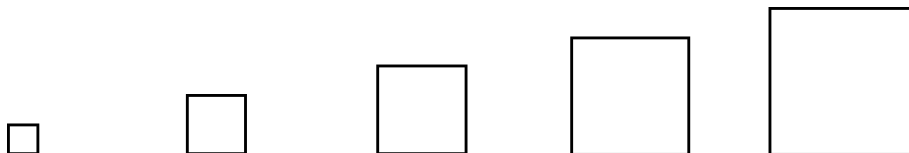
I: Have other pupils in the school ever made fun of you?

A horizontal row of five squares. The first square is the smallest, and each subsequent square to its right is progressively larger, representing a scale from 1 to 5.

|              |                          |                  |              |              |
|--------------|--------------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or<br/>twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|--------------------------|------------------|--------------|--------------|

### Question 2

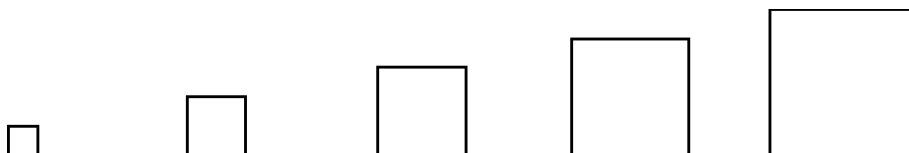
I: Do you like where you live?

A horizontal row of five squares. The first square is the smallest, and each subsequent square to its right is progressively larger, representing a scale from 1 to 5.

|              |                          |                  |              |              |
|--------------|--------------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or<br/>twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|--------------------------|------------------|--------------|--------------|

### Question 3

I: Do your parents treat you like you're different from other young people?

A horizontal row of five squares. The first square is the smallest, and each subsequent square to its right is progressively larger, representing a scale from 1 to 5.

|              |                          |                  |              |              |
|--------------|--------------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or<br/>twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|--------------------------|------------------|--------------|--------------|

Question 4

I: Have people in your home town ever made fun of you?

☐ ☐ ☐ ☐ ☐

| Never | Once or twice | Sometimes | Often | A lot |
|-------|---------------|-----------|-------|-------|
|-------|---------------|-----------|-------|-------|

Question 5

I: Have other people ever made you laugh?

☐ ☐ ☐ ☐ ☐

| Never | Once or twice | Sometimes | Often | A lot |
|-------|---------------|-----------|-------|-------|
|-------|---------------|-----------|-------|-------|

Question 6

I: Do teachers treat you like you're different from other young people?

☐ ☐ ☐ ☐ ☐

| Never | Once or twice | Sometimes | Often | A lot |
|-------|---------------|-----------|-------|-------|
|-------|---------------|-----------|-------|-------|

Question 7

I: Do you like to go into town?

☐ ☐ ☐ ☐ ☐

| Never | Once or twice | Sometimes | Often | A lot |
|-------|---------------|-----------|-------|-------|
|-------|---------------|-----------|-------|-------|

Question 8

I: Have people in your family ever made fun of you?

☐ ☐ ☐ ☐ ☐

| Never | Once or twice | Sometimes | Often | A lot |
|-------|---------------|-----------|-------|-------|
|-------|---------------|-----------|-------|-------|

Question 9

I: Do people in your home town treat you like you're different from them?

☐ ☐ ☐ ☐ ☐

| Never | Once or twice | Sometimes | Often | A lot |
|-------|---------------|-----------|-------|-------|
|-------|---------------|-----------|-------|-------|

Question 10

I: Do you like the school you go to?



|              |                      |                  |              |              |
|--------------|----------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|----------------------|------------------|--------------|--------------|

Question 11

I: Have teachers ever made fun of you?

|              |                      |                  |              |              |
|--------------|----------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|----------------------|------------------|--------------|--------------|

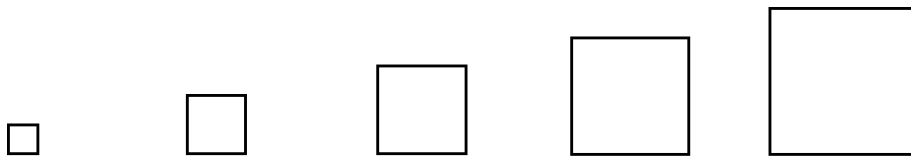
Question 12

I: Do you like to go to the cinema?

|              |                      |                  |              |              |
|--------------|----------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|----------------------|------------------|--------------|--------------|

Question 13

I: Do other pupils in school treat you different from them?



|              |                          |                  |              |              |
|--------------|--------------------------|------------------|--------------|--------------|
| <b>Never</b> | <b>Once or<br/>twice</b> | <b>Sometimes</b> | <b>Often</b> | <b>A lot</b> |
|--------------|--------------------------|------------------|--------------|--------------|

## Appendix 2.3: Adapted Rosenberg Self Esteem Scale

### 1. I feel that I am a good person, as good as others

|            |                  |                |            |             |
|------------|------------------|----------------|------------|-------------|
| Never true | Hardly ever true | Sometimes true | Often true | Always true |
|------------|------------------|----------------|------------|-------------|

### 2. I feel that I have a lot of good qualities

|            |                  |                |            |             |
|------------|------------------|----------------|------------|-------------|
| Never true | Hardly ever true | Sometimes true | Often true | Always true |
|------------|------------------|----------------|------------|-------------|

### 3. I am able to do things as well as most other people

|            |                  |                |            |             |
|------------|------------------|----------------|------------|-------------|
| Never true | Hardly ever true | Sometimes true | Often true | Always true |
|------------|------------------|----------------|------------|-------------|

### 4. I feel I haven't done anything worthwhile

|            |                  |                |            |             |
|------------|------------------|----------------|------------|-------------|
| Never true | Hardly ever true | Sometimes true | Often true | Always true |
|------------|------------------|----------------|------------|-------------|

### 5. I like myself

|            |                  |                |            |             |
|------------|------------------|----------------|------------|-------------|
| Never true | Hardly ever true | Sometimes true | Often true | Always true |
|------------|------------------|----------------|------------|-------------|

**6. At times I think I am no good at all**

☐☐☐☐☐

|            |                  |                |            |             |
|------------|------------------|----------------|------------|-------------|
| Never true | Hardly ever true | Sometimes true | Often true | Always true |
|------------|------------------|----------------|------------|-------------|

## **Participant Information Sheet**

### **The experiences of young people who get extra help in school**

You are being invited to take part in a research study. The research study is voluntary so you do not have to take part. Before you decide if you want to take part, it is important for you to know why the research is being done and what it will involve. This information sheet will tell you about these things.

#### **Who I am**

My name is Alasdair Cameron and I am a Trainee Clinical Psychologist. I am carrying out this study with help from my supervisor Professor Andrew Jahoda who is a University Professor and a Consultant Clinical Psychologist.

#### **What is this study about?**

This study is happening to help us understand more about how young people who get help at school are treated by other people. The study will also help us understand how young people feel about getting extra help and how they feel about other people.

#### **Why we are doing this study?**

It is important for us to understand how young people are treated, and how they feel about this. Knowing these things can help us find ways to make young people feel happier. The study Starts in October 2013 and ends in July 2013.

#### **Why have I asked you to do this study?**

You have been asked because you go to school in the Highlands and are 16 or older. I am trying to meet with 50 young people who go to school in the Highlands to find out more about how they feel about getting extra help in school.

#### **You do not have to take part in this study.**

It is up to you to decide whether or not to take part in this study. It is okay if you decide that you don't want to take part. You don't have to tell anyone why you don't want to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

It's also okay to start taking part in the project and then change your mind. You still won't have to give a reason for changing your mind and you will still keep the information sheet and consent form.

#### **What is involved?**

I would ask to meet with you for about 1 hour at your school. I might also ask you to meet with me for a second time to ask some more questions. The most time I would see you for would be 2 hours.

During our meeting I would read you two stories and ask you to answer questions about what you think of the characters in the stories. I would also ask about how other people have treated you in school, and outside of school and how you feel. I might also ask you to have a go at some puzzles.

I would write down your answers and I would record your answers on a voice recorder to help me remember the things that you have told me.

### **Benefits of taking part**

We won't give you a specific reward for taking part in our study. However, we hope that you will like telling us about your experiences. By taking part in the study you will help us to know more about the experiences of young people who get support at school. By understanding more about what it's like for you, we can find out more about how to help other young people.

### **What will happen to your information after we meet?**

All of the information that you give me in our meeting will be kept safe in a locked drawer and on a password protected computer. This means that no one apart from me and my supervisor will be able to see the information that you shared with me. The information will be kept securely and destroyed after 10 years.

### **What will happen to the results of the study?**

Once I have spoken to all the young people who want to be involved in the study, I will write about what I have found out in a paper that may be read by other people. None of the participants will be named in this paper so that no one else knows that I spoke to you. I might use direct quotes of what you have told me, but these won't include your name or any details about your life that might help people to identify you.

I can also give you a copy of the results of the study.

### **Other questions about the study**

If you have any more questions about the study then you can get in touch with me.

You can write to me at:

Or you can email me at:

Or you can call me on:

My supervisors contact details are:

### **If you are interested in taking part...**

If you would like to take part in this study then please complete the attached slip and give it to your class teacher or return it to me using the stamped addressed envelope.

**Thank you for taking the time to think about this study.**

---

I would be happy to meet with\_\_\_\_\_ to hear more about the study

Name\_\_\_\_\_

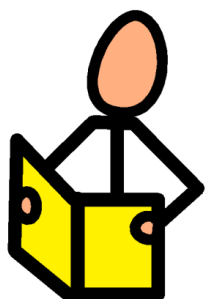
Date\_\_\_\_\_

---

Consent Form

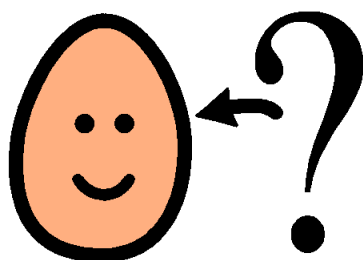
Names of researchers: Alasdair Cameron (Trainee Clinical Psychologist) and  
Professor Andrew Jahoda (Consultant Clinical Psychologist)

Please tick box:



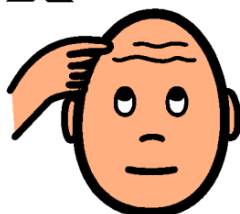
I have read and understood the information  
leaflet about taking part in the study.

**Yes**  ☐ **No**  ☐



I have had a chance to ask questions about  
taking part.

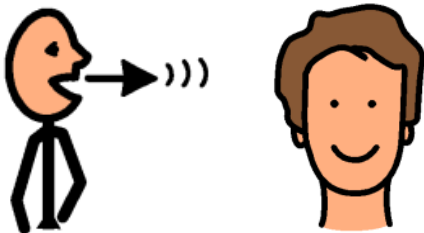
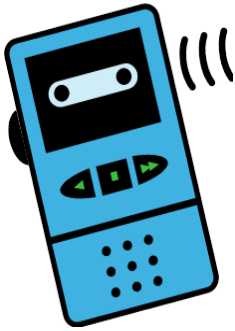
**Yes**  ☐ **No**  ☐



I understand that I am under no obligation  
to take part and can withdraw at any time,  
without giving a reason.

**Yes**  ☐ **No**  ☐





I am aware that the interview will be recorded by the researcher, Alasdair Cameron, and only used for the purpose of the current study.

Yes

☐

No

☐

I am aware and understand that the researcher, Alasdair Cameron, may publish direct quotations said by me during interview but these will not include any information about who I am.

I understand that all names, places and anything that could identify me will be removed and nothing that identifies me will appear for others to see.



I agree to take part in the study.

|     |   |                          |    |   |                          |
|-----|---|--------------------------|----|---|--------------------------|
| Yes |  | <input type="checkbox"/> | No |  | <input type="checkbox"/> |
|-----|---|--------------------------|----|---|--------------------------|

Name of participant

Signature

date

Researcher

Signature

date

Teacher/lecturer

Signature

date

## Appendix 2.5: Ethics approval letter

17<sup>th</sup> January 2014

Dear Alasdair Cameron and Professor Andrew Jahoda

### **MVLS College Ethics Committee**

**Project Title:** Stigma, Social Comparison and Self-esteem among Adolescents with Intellectual Disability and Autistic Spectrum Disorder.

**Project No:** 200130035

The College Ethics Committee has reviewed your application and has agreed that there is no objection on ethical grounds to the proposed study. They are happy therefore to approve the project, subject to the following conditions

- Project end date: July 2014
- The research should be carried out only on the sites, and/or with the groups defined in the application.
- Any proposed changes in the protocol should be submitted for reassessment, except when it is necessary to change the protocol to eliminate hazard to the subjects or where the change involves only the administrative aspects of the project. The Ethics Committee should be informed of any such changes.
- You should submit a short end of study report to the Ethics Committee within 3 months of completion.

Andrew C. Rankin

Professor of Medical Cardiology

BHF Glasgow Cardiovascular Research Centre

College of Medical, Veterinary & Life Sciences

University of Glasgow, G12 8TA

Tel: 0141 211 4833

Email: [andrew.rankin@glasgow.ac.uk](mailto:andrew.rankin@glasgow.ac.uk)

Yours sincerely

A handwritten signature in blue ink, appearing to read 'A.C. Rankin'.

Prof. Andrew C. Rankin  
Deputy Chair, College Ethics Committee



## **DOCTORATE IN CLINICAL PSYCHOLOGY**

### **SUBMISSION FRONT PAGE**

**Matriculation Number: 1010171c**

**Name of Assessment: MRP Proposal**

**Title of Project: Stigma, Social Comparison and Self-esteem among Adolescents with Intellectual Disability and Autistic Spectrum Disorder.**

**Academic Supervisor: Professor Andrew Jahoda**

**Version Number: 10**

**Word Count: 3314**

### **Proposal Amendment**

A pilot study was carried out using a semi-structured interview with one participant with mild ID and one participant with high-functioning ASD. The results indicated that although participants had described social comparison processes, they had only done this with prompting from the interviewer. Due to the considerable difficulties in recruiting an appropriate number of participants, it was decided to focus efforts on widening recruitment to other areas to ensure that between group comparisons were made possible.

# Stigma, Social Comparison and Self-esteem among Adolescents with Intellectual Disability and Autistic Spectrum Disorder

## Abstract

### *Background*

People with intellectual disabilities (ID) are at increased risk of experiencing stigma. Despite this they do not simply internalise a negative view of themselves. Social comparison is one social cognitive process that might help to facilitate individuals in protecting themselves from the negative evaluations of others. By comparing to individuals who are perceived as performing less well on an attribute (e.g. ability/behaviour) individuals can protect their positive self-identity. Individuals with autistic spectrum disorders (ASD) also have a higher risk of experiencing stigma. Little social comparison research has been conducted with ASD populations but there is evidence that they also use social comparison.

### Aims

This is an exploratory study which aims to examine the relationships between social comparisons, stigma and self-esteem for adolescents with ID and high functioning ASD (ASD without ID).

### *Methods*

The comparisons that participants with high functioning ASD or ID make to different targets will be measured using the Adapted Social Comparison Scale (SCS). Self-esteem and stigma experiences will also be measured.

Social comparison will also be explored using semi-structured interviews with both groups.

### *Applications*

Understanding how social comparison helps to protect self-esteem could help to develop strategies to improve the self-esteem of individuals with high functioning ASD/ID.

### Introduction

Goffman's (1963) description of stigma as an "attribute that is deeply discrediting" and that reduces the bearer "from a whole and usual person to a tainted, discounted one" has been widely cited (e.g. Link and Phelan 2001, Paterson, McKenzie, & Lindsay, 2012). The stigmatised status of individuals with intellectual disability (ID) has been described by a number of researchers, along with the potential impacts of stigma experiences on the self-esteem and self-concept in individuals with ID's. (Abraham, Gregory, Wolf, & Pemberton, 2002; Cooney et al., 2006; Corrigan, Kerr, & Knudsen, 2005; Huck, Kemp, & Carter, 2010). Stigma experienced by children with IDs is particularly concerning due to the increased risk of psychosocial problems within this group (Mishna, 2003).

Similar to individuals with ID, adolescents with autistic spectrum disorder (ASD) share experiences of receiving additional support within school or being educated within special educational settings (SES) and having increased risk of experiencing stigma (Ling et al., 2010; Shtayermman, 2009). Young people with ASD also have a higher risk of experiencing psychiatric disorders (Hedley & Young, 2006).

Experiences of stigma could be expected to contribute to the development of negative views of the self, for example Reflected Appraisal Theory (Gergen, 1977) proposes that individuals form their self-perceptions by internalising messages they receive from others. Accordingly it would be expected that individuals with ID/ASD who experience stigma would develop a stigmatised view of themselves which, in turn, would impact negatively upon their self-view. Although some studies with ID populations have identified a relationship between increased awareness of stigma and lower self-esteem (Paterson et al., 2012; Szivos-Bach 1993), a number of studies have also found that individuals with ID do not simply internalise a



negative view of themselves and tend to see themselves as similar to others (Cooney et al., 2006; Kelly & Norwich, 2004). Understanding the processes by which some individuals protect their self-view from the negative effects of stigma may offer opportunities to assist individuals who develop negative self-views.

One suggested mechanism by which individuals may be able to control the impact of negative experiences and messages have on their self-view is through social comparison (Festinger 1954). Social comparison theory proposes that individuals protect themselves from negative self-evaluations by making comparisons with others who are similar (or worse) than them in terms of specific skills or characteristics; as opposed to comparing with others who perform more highly in a given attribute (Szivos, 1991). Making selective “downwards” comparisons with individuals who perform less well may allow individuals to boost their self-view by focusing on placing their abilities or other personal characteristics above those of the chosen subject of comparison and avoiding comparisons that highlight their difficulties and membership of a stigmatised group (Cooney et al., 2006; Finlay & Lyons, 2000; Paterson et al., 2012). The salience given to specific attributes by the individual may also play an important role in how they view themselves (MacMahon & Jahoda, 2008), i.e. where they cannot select a target for comparison that provides a positive comparison, they may de-value the importance of the attribute in question.

Whilst social comparison within ID populations has received a very limited amount of study, social comparison processes within ASD populations has received even less study. It might be expected that the difficulties with social communication, interaction and imagination that form the basis of ASD (Humphrey & Lewis, 2008) would affect the social comparisons made by individuals with ASD. It is possible that their difficulties could cause them to withdraw from the social world rather than being motivated to make interpretations that benefit their self-esteem (Hedley & Young, 2006). Some social comparison studies have excluded ASD individuals due to their having different characteristics to ID populations (e.g. Cooney et al.,

2006). However, one of the few studies looking at social comparison within an ASD population (Hedley & Young, 2006) found a similar predictive relationship between social comparison scores and depression scores for ASD adolescents as has been found for ID, and non-ID populations. It is possible that individuals with ASD utilise similar social comparison processes as other individuals.

Structured measures such as the adapted Social Comparison Scale (SCS) ask that participants compare themselves to other people in general (Dagnan & Sandhu, 1999), or to a predefined target selected with input from the researcher (Cooney et al., 2006; Crabtree & Rutland, 2001). The SCS has been utilised with both ID and ASD populations (Dagnan & Sandhu, 1999; Hedley & Young, 2006). The use of qualitative interviews allows the exploration of how individuals use social comparisons within naturally occurring situations within their daily lives.

Examining the relationship between the social comparisons made by individuals with high functioning ASD and ID and their self-esteem will offer insight into how they maintain a positive sense of self despite their difficult social experiences. Existing measures offer a useful tool for exploring the relationship between self-esteem, social comparison and stigma. However, a qualitative approach such as that taken by Finlay & Lyons (2000) may be useful in gaining a deeper understanding of the types of comparisons individuals make within their daily lives.

### Aims and hypotheses

This is an exploratory study which aims to examine the relationships between social comparisons, stigma and self-esteem in adolescents who have been identified as having ID or ASD.

### Hypotheses

1. Adolescents with high functioning ASD and adolescents with ID will both make more positive social comparisons when comparing to a target with intellectual and social difficulties and will make more negative comparisons when comparing to a target without intellectual and social difficulties.
2. Experiences of stigma will correlate with self-esteem scores for adolescents with high functioning ASD and adolescents with ID.

### Research Questions

1. Do individuals with high functioning ASD and ID select different attributes for social comparison when describing their relative view of self?
2. Do individuals with high functioning ASD and ID make similar use of positive social comparisons when describing their relative view of self?

### Plan of investigation

#### *Participants*

Participants will be young people between the ages of 16 and 18 who have been identified as having a mild to moderate intellectual disability or high functioning ASD (without ID) by their schools.

#### *Inclusion/exclusion criteria*

Participants will either need to have been identified as having an intellectual disability, having an IQ below 70 (DSM-IV), or have been identified as having high functioning ASD.

Individuals who have been identified as having both ID and ASD will be excluded from the study.

Individuals with more severe ID who may be unable to complete the tasks will be excluded from the study.

Individuals with severe visual or hearing impairment which may prevent them from engaging with research materials will be excluded from the study along with those who do not speak fluent English.

### *Recruitment procedures*

Schools providing support to individuals with high functioning ASD and ID, within the Highland region, will be approached and asked if they are willing to participate in the current research project. Due to the challenges of finding participants from these groups, both mainstream schools and non-mainstream schools will be contacted. Schools that opt in will be asked to identify groups of students who they believe have mild-moderate Intellectual Disabilities, or who have high functioning ASD, who may be approached for recruitment.

All young people will be provided with accessible information about the current project (*Appendix H*) and will be asked to provide verbal and written consent (*Appendix I*) to participating in the current study. They will be reminded of their right to withdraw at any time at each meeting.

### *Design*

The proposed study will use a mixed-method design and be largely exploratory.

The first part of the study will involve the use of quantitative methods to examine the relationship between social comparison, self-esteem and stigma for individuals with ID and high functioning ASD.

The second part of the study will involve a semi-structured interview examining social comparisons made without being prompted to select a comparison group and will be

conducted with a sub-sample of individuals from each of the groups. Content analysis will be used to identify the type of comparisons made by individuals with ID, the targets of their comparison and the attributes on which they choose to make comparisons of different types. Finlay and Lyons (2000) operational definition of social comparison as being “when people presented their own and other people’s standings on some attribute so as to allow comparison” (p7) will be used within the proposed study

### *Measures and Semi Structured Interview*

Self-Esteem: The adapted Rosenberg Self Esteem Scale (Dagnan & Sandhu, 1999) (appendix a) is a 6 item measure of self-esteem using a visual scale of increasing blocks corresponding to the level of agreement indicated with participants asked to rate each statement as “never true”, “hardly ever true”, “sometimes true”, “often true” or “always true”. The test has been found to have an alpha value of 0.62 (Dagnan & Sandhu, 1999).

Social Comparison with peers: The Adapted Social Comparison Scale (SCS) (appendix b) adapted for people with intellectual disabilities will be used to investigate the nature of the participants’ social comparisons (Dagnan & Sandhu, 1999). The scale presents participants with an incomplete sentence and asks them to compare themselves to a target individual by choosing between two bi-polar constructs by pointing to a point on a visual analogue scale. One item will be removed from the scale “When I am with (target) I generally feel (the same/different)” as this was found to increase the Cronbach alpha to 0.72 from 0.58 (MacMahon & Jahoda, 2008)

Stigma: the Experience of Stigma Checklist (appendix c) (Cooney et al., 2006) is a 13-item self-report scale. Eight items concern the frequency with which participants experience stigmatised treatment from key figures in their lives (parents, teachers, school pupils, and people in the local area) through being treated differently or made fun of, and five items

concern the frequency of non-threatening experiences. The scale uses a 5 point visual analogue scale with a verbal prompts, and has an alpha value of 0.61.

Level of cognitive ability: The Wechsler Abbreviated Scale of Intelligence (WASI) (Wechsler 1999) is a brief measure of intelligence which has been shown to be reliable with adolescent populations. The average reliability coefficient of the WASI is 0.98-0.96. Test retest reliability is 0.92 -0.88. Inter-rater reliability is 0.98 for vocabulary and 0.99 for similarities. The WASI will be used to indicate the level of cognitive functioning of participants within the ID group.

Semi-structured Interview to Elicit Naturally Occurring Social Comparisons (appendix d):

The aim of this interview is to explore the social comparisons participants make when they describe their relative view of self without prompting to select a particular target (Finlay & Lyons, 2000). The interview will consist of two different areas of focus, within school "school" and out-with school "social activities".

The interview will begin by asking participants to describe social activities that they engage in outside of school, and questions about their interests within school, e.g. favourite and least favourite class. The aim of this is to provide an opportunity for rapport building and to find examples of salient activities for individuals to use for social comparisons.

Once specific examples have been identified, participants will be asked to provide more information about the situations that they have described. If they provide multiple examples for one category e.g. preferred activity they will be asked to select one area for comparison.

Participants will next be asked to describe their performance in relation to others i.e. areas of comparative strength/weakness. Further prompts will be used to identify whether or not they view their target for comparison as having ASD or ID difficulties, e.g. "Do they need special help from teachers".

An initial pilot will be conducted with 2-3 individuals to examine whether the question schedule is suitable in producing social comparison and stigma views of young people with IDs/high functioning ASDs within a suitable time.

### *Research Procedures*

The researcher will meet a selection of participants for two occasions.

#### Meeting 1

- i. Following introductions and reminding of ethical considerations and building rapport, participants will be read one of 2 vignettes (Cooney et al., 2006) and will be asked to complete the adapted SCS in comparison to the individual described within the Vignette (the order of presentation of vignettes will alternate for each participant). Each question will be presented in large print on an A4 sheet along with a visual analogue scale, and will be read aloud.
  - a. Vignette 1: will describe a peer who has features of both ASD and ID, such as requiring assistance to get up and dressed, and requiring constant assistance in school from a carer, and struggling to make and maintain friends
  - b. Vignette 2: will describe a peer who gets themselves up in the morning and walks to the local bus stop, does not receive any assistance in school and has a number of friends
- ii. Participants will be read the alternate vignette and asked to complete the adapted SCS for a second time following the same procedures as before.

- iii. Participants will be asked to complete the experience of stigma checklist. Each question will be presented in large print on an A4 sheet along with a visual analogue scale and will be read aloud.
- iv. Participants will subsequently be asked to complete the adapted Rosenberg Self Esteem Scale, with each question presented on an A4 sheet with a visual analogue scale, and read aloud.
- v. Both groups will be asked to complete the WASI (short form) to provide an estimate of cognitive ability.

## Meeting 2

- i. A subsample of participants will be asked to return to complete a semi-structured interview. The interview will be recorded on an MP3 player, provided by the researcher, for subsequent transcription.

## Follow up

Participants will be provided with a summary of the research following completion of the project if they would like to receive this.

## *Data Analysis*

Quantitative analysis: the three variables of social comparison, self-esteem, and stigma, will be evaluated to ascertain whether they met parametric assumptions using a Kolmogorov–Smirnov test. Where data does not meet parametric assumptions, if possible, they will be transformed using the square root, log and inverse.

In order to test the first hypothesis the two SCS scores (comparing to more able/less able target) will be analysed within the ID and high functioning ASD group, and between the ID



and high functioning ASD group. Where parametric assumptions have been met an ANOVA test will be used. If parametric assumptions are not met Mann-Whitney U tests will be used.

To test the second hypothesis, a correlation analysis will be conducted between stigma and self-esteem scores within both the ID and high functioning ASD groups. If data meet parametric assumptions, Pearson's correlation will be conducted; otherwise a Spearman's correlation will be conducted.

Qualitative analysis: Following transcription of interviews, content analysis will be used to describe the types of social comparisons made (downwards/upwards/lateral) (Finlay & Lyons, 2000), the attributes used to make different comparisons (e.g. behavioural conduct, academic ability, physical ability) and the target of comparison (e.g. with/without pervasive developmental disorder).

#### *Justification of Sample Size*

The proposed study is exploratory and no study using a between groups design with ASD and ID populations was identified. Power calculation has therefore been calculated for the relationship between stigma and self-esteem. Paterson, McKenzie, & Lindsay (2012) found an effect size of 0.41 for a correlation between the adapted Rosenberg self-esteem scale and the Stigma Perception Questionnaire (Szivos 1991), which is an alternative measure of measuring self-esteem. A power calculation was carried out using G\*Power software based on a moderate effect size. For a power level of 0.8 at the 5% level of significance it was calculated that the sample size required for a one tailed correlation would be 35 for each group. However due to the exploratory nature of the proposed research, the challenges of accessing individuals with high functioning ASD and ID, and the mixed methods approach being taken, it is proposed that 25 participants will be recruited per group.

There is wide variation in sample sizes for studies using content analysis (Reis & Judd 2000)

The proposed study aims to use content analysis as a means of exploring the types of naturally occurring comparisons made by participants. This will provide information as to whether naturally occurring comparisons made within interviews are consistent with participant's responses within structured questionnaires. Interviews will be conducted with a sub-sample of 10 participants from each group.

### *Settings and equipment*

Participants will be interviewed within the school setting, although this may provide a cue for them to focus on the academic setting it is felt that this is the most suitable location to carry out interviews in a familiar environment minimising the disruption for participants from their daily routine.

### Health and Safety Issues (Appendix F)

Testing will take place within schools which should be a predictable environment for participants. Participating schools will be asked to provide a quiet space for testing to take place, and will be asked to inform the researcher of any additional concerns for individual participants. Schools will also be asked to provide a contact for any concerns arising during data collection, such as participants becoming distressed.

### Ethical Issues

There are inherent power issues in asking young people and particularly young people with developmental disabilities, to take part in research. As well as being asked to provide verbal consent, participants will be provided with an accessible information sheet explaining that they can stop participating in the study at any time and will be reminded of their right to withdraw from research at each meeting with the researcher. Any individual unable to provide informed consent will not be recruited for the study.

Data will be anonymised and both written data and audio recordings will be stored in a locked cabinet in a locked room under the terms of the data protection act (1998). An encrypted laptop will be used to store and analyse data.

As ID participants are based within mainstream schools they will be contacted via the additional support base within school following permission being granted from the local head of education and head teachers. All participants will be provided with information sheet that invites themselves or their parents' to contact the researcher for discussion of research.

#### Financial issues

*See Appendix G*

#### Timetable

October 2013: re-submit proposal to university

October-November 2013: Seek ethical approval from university and education department

November-December 2013: commence recruitment

May 2014: Analysis

June-August 2014: write up

August 2014: submit research to university

September 2014: viva

#### Practical Applications

It is widely recognised that individuals with intellectual disabilities and ASD experience significant stigma throughout their lives (Hedley & Young, 2006) and this is true for children and young people as well as adults (Cooney et al., 2006). It has also been recognised that stigma is a predictor of psychological problems (Mishna, 2003) for individuals with ID.

Understanding processes that may help individuals with ID/ASD protect their self-esteem in

the face of stigmatising experiences will help in offering practical methods to assist young people with ASD/ID in protecting and improving their well-being.

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# WEST OF SCOTLAND/ UNIVERSITY OF GLASGOW

## DOCTORATE IN CLINICAL PSYCHOLOGY

### HEALTH AND SAFETY FOR RESEARCHERS

|   |  |
|---|--|
| 1. Title of Project   | Prompted and Real world Social comparisons of young people with Intellectual Disability and Autistic Spectrum Disorder.  |
| 2. Trainee  | Alasdair Cameron   |
| 3. University Supervisor  | Professor Andrew Jahoda  |
| 4. Other Supervisor(s)  |  |
| 5. Local Lead Clinician   |  |
| 6. Participants: (age, group or sub-group, pre- or post-treatment, etc) | 16-18 year olds with Autistic Spectrum Disorders or Intellectual disabilities.   |
| 7. Procedures to be applied<br>(e.g., questionnaire, interview, etc)    | Questionnaires: Adapted Social Comparison Scale (Dagnan and Sandu 1999), Adapted Rosenberg Self-Esteem Inventory (Dagnan and Sandu 1999), Experience of Stigma Questionnaire (Cooney et al 2006), The Wechsler Abbreviated Scale of Intelligence (Wechsler 1999).<br><br>Semi-structured Questionnaire to elicit social comparisons. |
| 8. Setting (where will procedures be carried out?)<br><br>i) General    | The research will take place within schools.   |
| ii) Are home visits involved  | N  |

|  |   |
|--|---|
| <p>9. Potential Risk Factors Identified</p> <p>(see chart)</p> | <p>Adolescents with ASD/ID may react unpredictably to emotive discussions.</p>  |
| <p>10. Actions to minimise risk (refer to 9)</p>               | <p>Participants will be provided with accessible information explaining that they may stop participating at any time. Schools will be asked to inform the researcher of any participants who are at risk of becoming upset from participating in research.</p> <p>Pre-existing measures which have been used successfully with adolescents are used where possible. The newly developed semi-structured interview does not mention areas of self-esteem or stigma, which may be emotionally challenging, and focuses on naturalistic comparisons.</p> |

Trainee signature: ..... Date: .....

University supervisor signature:..... Date: .....

### *Appendix G: Stationary Costs*

Please complete the list below to the best of your ability

| Item  | Details and Amount Required | Cost or Specify if to Request to Borrow from Department |
|---|-----------------------------|---|
| Stationary  | N/A                         | Subtotal: -   |
| Postage   | N/A                         | Subtotal: -   |
| Photocopying and Laser Printing ( <b>includes cost of white paper</b> ) |                             | Subtotal:   |
| Equipment and Software  | N/A                         | Subtotal: -   |
| Measures  | WASI x50                    | Subtotal: £75.00  |
| Miscellaneous   | N/A                         |   |

|              |  |             |
|--------------|--|-------------|
|              |  | Subtotal: - |
| <b>Total</b> |  | £156        |

**For any request over £200, please provide further justification for all items that contribute to a high total cost estimate:**

While 3 of the outcome measures used are free, the further 4 listed are for a sufficient number of essential scoring sheets only. The manual and stimulus books will be borrowed from the department.

Trainee Signature..... Date.....

Supervisor's Signature ..... Date .....